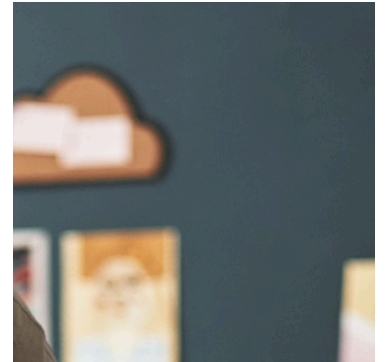


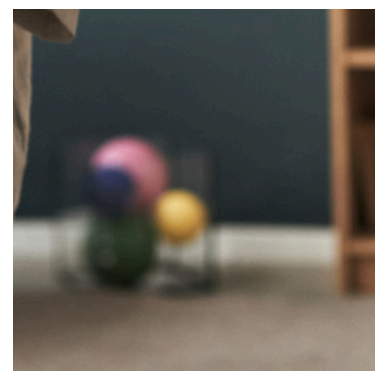
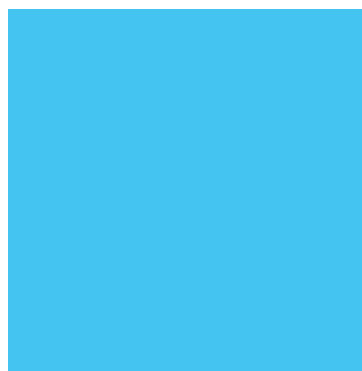
Policy Agenda

2026-2027

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



Explore More



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, Olmstead, and Americans with Disabilities Act, support our work. Family Voices' history is deeply tied to the fight for disability rights that is rooted in these policies and legal decisions. Our founders played a key role in the creation of home- and community-based services, specifically Katie Beckett/ TEFRA Waivers which provide access to home-based care for children with complex medical needs based on their income alone.

Through the continued efforts of Family Voices, Family Voices Affiliate Organizations, and the Family-to-Family Health Information Centers, families are able to connect to home- and community-based services in their communities.

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.

Over the past few decades, we have built and maintained strong partnerships with family-led and professional organizations to help champion our policy priorities. Despite changing federal priorities, Family Voices continues to advocate for programs and policies that best serve children and youth with special health care needs and disabilities. Our objective is to develop policy and legislation with full family engagement and improve systems of care for CYSHCN and their families. We continue to support youth and family leaders so they can advance policy priorities that bring us closer to our organizational vision that all children, youth, and families, especially those with special health care needs and disabilities, experience their best health and quality of life.



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 system barriers 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.

When federal priorities do not align with best practices, we must adapt our strategy to best support CYSHCN across all areas of health systems and policy. Following a year of unprecedented cuts and changes to the programs that support children and youth with special health care needs and their families (CYSHCN), Family Voices worked with families to adjust and focus our policy priorities.

Families continue to feel the impacts of the changing policies and many are becoming more involved in shaping the policies that impact their lives. The process of policymaking needs to:

- Center the voices of children, youth, and families through all stages of life.
- Foster collaboration among people with lived experience, health care professionals, and policymakers.
- Prioritize disease prevention, innovation, partnership, and overall quality of life.

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 and youth 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-led organizations and our programming.
- Maintain adaptability and responsiveness to shifts in the political landscape.



Family engagement contributes to the development and improvement of effective health policies that improve services and care delivery (AHRQ, 2020).

Our Policy Focus

Family Voices was founded through family-led advocacy and legislative action. As we continue to expand our presence in the policy space, our focus for the coming year will be on protecting and advancing legislation and policies that improve systems of care for CYSHCN.

To make the most impact, we focus our policy actions across all levels of the federal government, building on the work and learnings from states and local communities.

We continue to work with our family and organizational partners to lean on the various levers of policy change through education and advocacy.

In addition to advancing our policy priorities, our goals include:

- Ensuring that our network of family-led organizations is supported in their efforts to engage and educate policymakers.
- Collaborating with partners who work with and represent health professionals, ensuring that family priorities are represented in policy conversations.
- Ensuring families and youth play key roles in shaping and implementing Family Voices' policy priorities and actions.
- Expanding partnerships with families, communities, organizations, and funders to advance equity and improve quality of life for CYSHCN and their families.

Finally, we work with stakeholders and partner networks to coordinate national resources and initiatives and center the needs of children and youth with special health care needs and disabilities, their families and caregivers.



Engaging families in policy design, advisory groups, and decision-making strengthens health systems (Dworetzky et al., 2023).

Strategic Policy Priorities

Key policies Family Voices and our partners have pushed to support CYSCHN and their families include:

Family-to-Family Health Information Centers (F2F)

Family Voices, our network, and our partners continue to advocate for support of F2F reauthorization and increased funding. F2Fs provide critical support to families of children and youth with special health care needs (CYSHCN) and disabilities. These supports include helping families understand their health coverage; coordinating appointments, services, and medications; peer-to-peer counseling; and promoting leadership training and development. These no-cost services are provided by family members of CYSCHN with first-hand experience navigating health care and other needed services and supports for their children.

This results in improved outcomes for children and their families, including improved transitions from pediatric to adult health care systems; fewer unmet health needs; fewer problems with specialty referrals; lower out-of-pocket costs; and increased access to preventive health care in a medical home.

Access to Medicaid for CYSHCN

Since the passing of H.R.1, Medicaid coverage has been at risk. Families with Medicaid face new rules and additional paperwork about work reporting, coverage renewals, and eligibility for coverage and services. These requirements can confuse families with more forms to complete, which can cause people to lose coverage.

Also, “community engagement” or work requirement exclusions do not offer appropriate exceptions for CYSCHN and their families/caregivers, who are often unable to maintain employment because of intense and unpredictable care demands that can disrupt work schedules, require last-minute changes, and make it hard to maintain consistent attendance and performance. Family Voices has developed and supported letters and testimonials to support Medicaid. Family Voices also responded to the Department of Justice’s legal memo on Olmstead, firmly stating our support for home- and community-based services.

Caregiver Supports

In recent months, federal support for caregivers and the important work they do has been included in the Administration's "crackdown on fraud."

Family Voices, in partnership with our network of family and youth leaders, developed a set of policy recommendations for supporting and engaging caregivers ([English](#)/[Español](#)) across various levels of care – individual, community, and systems. We collaborated with families to develop a new definition of caregivers that highlights the important role they play in the lives of CYSHCN across their lives.

Continued Funding for Maternal and Child Health Programs

Maternal and child health (MCH) and CYSHCN outcomes are deeply connected. Support for mothers during and after pregnancy, as well as for children's health, can improve outcomes and increase connections to critical services and supports. In the last two proposed Federal Fiscal Budgets, MCH programs received large proposed cuts or eliminations.

Family Voices is part of multiple coalitions to support disability, child health, children with medical complexity, and other specific populations whose health is threatened by changing federal priorities.

As we address the current policy environment and look to the future, our grassroots approach to change and partnership will protect and build support for CYSHCN and their families by:

- Providing technical assistance and support to family-led organizations through office hours, policy listening sessions, webinars, and plain language resources.
- Developing a pipeline of new family and youth leaders through a series of leadership academies, Youth as Self Advocates (YASA), and the Julie Beckett Policy Academy.
- Identifying, co-creating, and advancing legislation with our network of family and youth leaders.
- Building on our partnerships with trusted messengers to help advance federal policy through messaging campaigns, Hill briefings, and connections with our network.

Strategic Policy Priorities (2026-2027)

Family Voices is focused on the broad policy space that impacts children and youth with special health care needs (CYSHCN) and their families. These updated policy priorities were refined in collaboration with family and youth leaders.



Expand Access to Peer-to-Peer Support

- Reauthorize and increase 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 – care coordination, financing, community health workers, hospital advisory councils, etc.



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

- Medicaid as the core support for people with disabilities across the lifespan
 - Coverage for home and community-based services (HCBS) and caregiving, including home nursing, paid family caregiving and respite care
- Ensure that EPSDT is implemented to its highest standard
- Adapt/update the definition and usage of the “medically frail” classification to ensure it reflects the needs of those it is intended to support



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

- Elevate the voices of youth through youth leadership training and partnerships with youth-serving organizations
- Build on the Family Voices’ recommendations for supporting caregivers
- Advocate for supported decision making as an alternative to guardianship



Eliminate Language Access Barriers

- Promote plain language federal guidance and legal supports for language access
- Ensure Family Voices and our network of family-led organizations provide relevant and accessible policy resources for CYSHCN families in all communities across the U.S.
- Improve coordination/communication among other systems that children interact with (i.e. schools, insurance, and transportation) and the health sector