



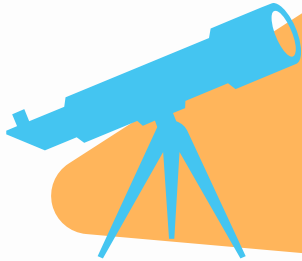
Strategic Framework

2024-2029



www.familyvoices.org

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.



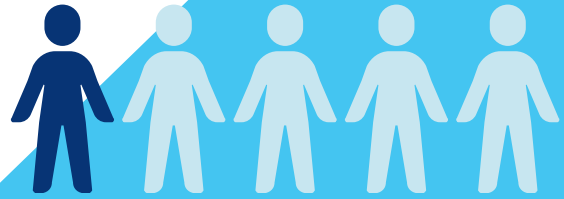
Our Values

The work of Family Voices is rooted in deeply held values shared with children, and youth with special health care needs and disabilities and their families. Our values include:

- Our power as change agents, partners, and experts on our lives.
- A health justice approach to achieve health equity.
- Family and person-centered care.
- The priority of our dignity, autonomy, and well-being.
- Including all of us equitably across race, ethnicity, class, culture, language, religion, disability, gender, sexual orientation, geographical location, and other characteristics.
- Our meaningful engagement in decision-making and advocacy.
- Authentic partnership and close collaboration across generations, communities, organizations, systems of care, and governments.

Introduction

In the United States, 18.8% of children and youth have special health care needs. The terminology for children and youth with special health care needs (CYSHCN) has evolved over the last 80 years. Health Resources and Services Administration (HRSA) defines children and youth with special health care needs as children who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.



One in five 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.

Program Focus

With the inclusion of at-risk children and youth as part of the definition of CYSHCN, 100% of Family Voices programmatic work focuses on CYSHCN and children with disabilities. Our work to meet the needs of CYSHCN and their families includes:

- Increasing access to resources and information
- Connecting families to Family to Family Health Information Centers (F2Fs)
- Building the capacity of family-serving organizations
- Supporting and transforming systems that serve families (upstream work)
- Training family leaders and engaging them in systems transformation
- Creating opportunities for families to feel heard and connect to services and systems
- Training professionals/partners to engage with families
- Sharing effective models and strategies for engaging and supporting families

While we have the skills and desire to address the needs of CYSHCN, we have limited funding and staffing to meet the demands and needs of the CYSHCN population.

Policy

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. However, 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.

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. The political landscape and need for bipartisan champions for F2F funding put F2Fs and Family Voices at risk of extinction.

This reality impacts the individual, community, and systems-level services that 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.

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.

Family Voices has continually taken a grassroots approach to our work, which is how our organization began. Policy consultants have worked hard to establish an educational campaign for F2Fs to engage in grassroots efforts to increase and maintain funding. Our network has indicated both a desire for additional funding and policy updates on legislation and regulations affecting CYSHCN to share with families; however, these have not increased actual grassroots advocacy within the network. The combination of limited grassroots efforts and political will can have impactful consequences on Family Voices' ability to carry out our mission.

Funding

Considering the challenges with the political landscape, Family Voices must consider other funding mechanisms, partnerships, and champions to carry our work forward and ensure our survival. Family Voices has longstanding relationships with the Maternal and Child Health Bureau (MCHB) but must consider the other federal funders that can be linked to our work.

These agencies include the Substance Abuse and Mental Health Services Administration (SAHMSA), Administration for Community Living (ACL), Office of Minority Health (OMH), and the Administration for Children and Families. Many of these agencies have larger and more flexible budgets, and their overall goals and missions align with the mission of Family Voices.

The financial position of Family Voices has changed exponentially over the last three years. Prior to the pandemic, Family Voices did not seek funding from a variety of sources. We relied solely on funding from the Maternal and Child Health Bureau, as well as funding from partners who came to us for support. While we have intentionally expanded our funding partners and sources, we are still largely dependent on federal grants. With very little unrestricted operating funding, our funding is at continual risk due to the effects of changes in administration, legislative priorities, or realignment. In addition to federal partners, Family Voices is pursuing grants and partnerships with private funders to fill the gaps that exist due to political changes. Additionally, it is important to seek unrestricted funds to provide a stable infrastructure for Family Voices' work.

Partnerships

In addition to the need for stable financial support to carry out our mission, Family Voices needs effective, committed partners in order to live out our mission and reach our goals and vision. Partnerships with key stakeholders have helped Family Voices reach our outlined mission and vision over the years. Family Voices has worked with our partners to improve family engagement, partnerships, family-centered care, and health equity for CYSHCN. We have held long-standing partnerships with influential organizations such as the American Academy of Pediatrics and Maternal and Child Health Bureau. Furthermore, we have built partnerships with other entities including F2Fs, FVAOs, Title V agencies, health systems, hospitals, private funders, non-profit organizations, government funders, provider organizations, legislators, academic institutions, research networks, and policy-related entities.

Some of these partnerships have become challenged and/or calcified over time, as more organizations are seeking to address engagement and equity. Family Voices has a unique opportunity to communicate who we are, what we do, our relationship to the network, and the scope of our family engagement work.

A critical element of our partnerships has been the network of Family Voices' Affiliate Organizations (AOs). The AO network is the bedrock of Family Voices, as they align with our mission and values, and they strengthen our reputation and reach. Historically, AOs received priority preference for funding opportunities from Family Voices. Additionally, Family Voices provided policy support to AOs to help build state advocacy for policy changes impacting CYSHCN. Family Voices is working to expand and enrich the special activities offered to AOs in order to increase their return on investment.

AOs are also challenged by a need for funding, which places Family Voices in a constant balance of directing our fundraising efforts toward our organization or toward the AO network.

Both the F2Fs and AOs are central to our connection to a network of organizations whose work is critical to fulfilling our mission.



In order to continue our growth and carry out our mission, it is essential for Family Voices to maintain existing partnerships while widening our circle. Intentional steps to expand our partnerships with entities such as hospitals, medical practices, health systems, Children's Hospital Association, AAP chapters, Administration for Children and Families, and child welfare organizations are critical to increasing knowledge about the needs of CYSHCN and fostering innovation to address these needs. Our reputation as an organization concerned about the health of children and about health equity makes us a sought-after partner, and we should continue to capitalize on this reputation to broaden our impact.

Looking Ahead

As we look ahead, we need to take into consideration the realities of what families of children and youth with special health care needs face every day. In the United States, children and youth with special health care needs and disabilities face systemic barriers and biases that impede their experiencing their best possible lives. Systems of care do not respond to their needs holistically nor facilitate access to supports that enhance quality of life.

Consequently, to address these challenges, we must be strategic in our approach to this work. Three key strategies that we must employ to reach our desired goals are building capacity, widening our circle of influence, and facilitating family-led transformation. Building the knowledge, skills, and resources of our staff, network, and partners to meet the needs of families and prioritize the expertise of families from minoritized communities is critical to meeting our goals over the next 5 years.

As we work to build capacity in the field of maternal and child health, we must widen our circle of influence by expanding our partnerships, establishing an evidence base for our work so we can demonstrate the impact of family engagement, and diversifying our funding sources. Building capacity and widening our circle of influence will allow us to effectively facilitate family-led systems transformation. Our identified values, mission, and vision will allow us to effectively employ these three strategies, which will enable us to meet the following goals over the next 5 years.



Strategic Priorities

Five-Year Goals



Build Capacity

Support youth, families and family-serving organizations to define and address systemic barriers and biases impacting the quality of life and well-being for CYSHCN and their families.



Advance Health Equity

Advance equity by reducing systemic barriers including ableism, racism, and other forms of discrimination that improve quality of life and well-being for CYSHCN and their families.



Lead Transformation

Enable and promote innovation within Family Voices and our work to improve the lives of CYSHCN.



Widen Our Circle

Secure diverse funding to enhance program work, policy efforts, and organizational evaluation.





Build Capacity

Goal 1: Support youth, families and family-serving organizations to define and address systemic barriers and biases impacting the quality of life and well-being for CYSCHN and their families.

- **Objective 1A:** Strengthen the knowledge, skills, and abilities of staff to effectively engage in national initiatives
- **Objective 1B:** Strengthen the knowledge, skills, and resources of the F2F and FVAO network to meet the needs of families
- **Objective 1C:** Strengthen the knowledge, skills, and abilities of the health care community to effectively engage families in systems transformation.
- **Objective 1D:** Strengthen the knowledge, skills, and abilities of youth and families to engage in community and systems transformation.



Advance Health Equity

Goal 2: Advance equity by reducing systemic barriers including ableism, racism, and other forms of discrimination that improve quality of life and well-being for CYSHCN and their families.

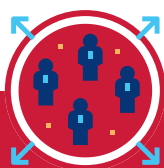
- **Objective 2A:** Develop health equity objectives and apply health equity metrics across integrated program and policy initiatives.
- **Objective 2B:** Identify and close gaps in program outcomes for historically underserved and/or marginalized populations across Family Voices' programs.
- **Objective 2C:** Center and integrate the perspectives and experiences of families and family-led organizations in the design, management, evaluation, and decision-making of FV programs and operations
- **Objective 2D:** Develop and implement anti-racist, anti-ableist, equity-focused data collection and reporting objectives and practices.
- **Objective 2E:** Expand partnerships with families, communities, organizations, and funders to advance equity and improve quality of life for CYSHCN and their families.



Lead Transformation

Goal 3: Enable and promote innovation within Family Voices and our work to improve the lives of CYSHCN.

- **Objective 3A:** Develop and maintain clear and consistent operational and communications policies, procedures, and practices, that embody our DEIB values.
- **Objective 3B:** Produce materials that are accessible, culturally responsive, and available in multiple languages and modes.
- **Objective 3C:** Establish structures, processes, and tools that incorporate innovation in the culture and operations of FV.
- **Objective 3D:** Improve employee engagement, experience, capacity, and well-being, especially during high-pressure periods.
- **Objective 3E:** Strengthen evidence-building activities and expand access to and use of data to improve the design and delivery of FV programs.
- **Objective 3F:** Utilize the DEIB Framework to guide recruitment, hiring, advancement, and employee satisfaction.
- **Objective 3G:** Remain appropriately staffed with professionals trained in and accountable to transparent and inclusive organizational practices, policies, and procedures.



Widen Our Circle

Goal 4: Secure diverse funding to enhance program work, policy efforts, and organizational evaluation.

- **Objective 4A:** Identify and apply for funding from diverse funding sources.
- **Objective 4B:** Build relationships with foundations to address the need for unrestricted funding to support lobbying and organizational evaluation.
- **Objective 4C:** Apply for and receive unrestricted grant funding to expand the infrastructure and evaluation capacity of Family Voices.