



2025

ANNUAL REPORT



familyvoices.org

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Message from Our Executive Director

Dear Friends,

Family Voices is excited to share our accomplishments from 2025! In a time of change and shifting national priorities, we are grateful to have been able to continue our work to transform systems of care for children and families.

Family Voices' programs continue to collectively strengthen family engagement, elevate equity, build national capacity, and influence systems of care for children and youth with special health care needs (CYSHCN).

In this report, you will find information about our projects, finances and goals that not only demonstrate what we do but also show the impact on those we serve through technical assistance, training, and support.

We selected new Board members, initiated new programs and zealously drove forward our strategic goals. Our partners and funders committed to family engagement and stood with us as thought partners and through tangible support. Our staff continued the excellent work that has built our reputation as the premier national voice on family engagement in systems of care.

All in all, 2025 was an outstanding year, and we couldn't have done it without partners like you. Thank you for all you do to support our mission!



Allysa Ware, PhD, MSW

Executive Director, Family Voices, Inc.



Who We Are and What We Do

Family Voices is a family-led nonprofit organization that transforms systems of care to work better for all children and youth, especially those with special health care needs or disabilities.

We work with organizations and initiatives to build their capacity for engaging youth and families in their work. Family Voices also supports a network of family-led and family-serving organizations across the country to meet the needs of their communities.

3 million

Over 3 million children in the US had a disability in 2019, up 0.4% since 2008.



One in four children in the US has special health care needs, which means they require more care and health services than other children.

4x

Children with special health care needs are nearly four times as likely to have unmet health care needs.

Our vision is that all children, youth, and families, especially those with special health care needs and disabilities, experience their best health and quality of life.





Our Values

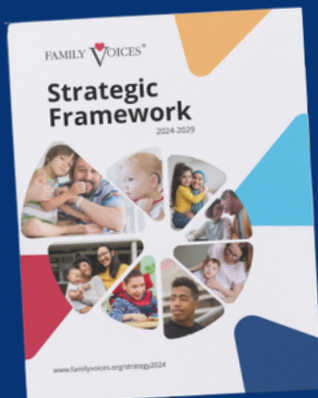
- Our power as change agents, partners, and experts on our lives
- A health justice approach to achieve health equity
- Family- and person-centered care
- The priority of our dignity, autonomy, and well-being
- Including all of us equitably across race, ethnicity, class, culture, language, religion, 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

Measuring Our Progress

In 2025, Family Voices continued to work toward the strategic goals we identified in 2024. We began working with an external evaluation firm, Bright Research Group (BRG), to better measure and evaluate the impact of our work. With BRG, we have developed an evaluation guide that we will implement in 2026 to track our progress, tell our story, and share how the work we do pushes us toward 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.**

Our four strategic goals are to:

| | | | |
|---|--|--|---|
|  <h3>Build Capacity</h3> <p>Support youth, families and family-serving organizations to define and address systemic barriers and biases impacting the quality of life and well-being of CYSCHN and their families.</p> |  <h3>Advance Health Equity</h3> <p>Advance equity by reducing systemic barriers including ableism, racism, and other forms of discrimination to improve quality of life and well-being for CYSCHN and their families.</p> |  <h3>Lead Transformation</h3> <p>Enable and promote innovation within Family Voices and our work to improve the lives of CYSCHN.</p> |  <h3>Widen Our Circle</h3> <p>Secure diverse funding to enhance program work, policy efforts, and organizational evaluation.</p> |
|---|--|--|---|



Throughout this report, we share the projects, initiatives and partnerships that advance our strategic goals. You can learn more about our goals by reading our 2024-2029 Strategic Framework document at familyvoices.org/strategy2024.

Building Capacity

Family Voices has strengthened the capacity of organizations across the maternal and child health (MCH) ecosystem by expanding knowledge, skills, infrastructure, and collaborative practices.

Our efforts have significantly improved the ability of organizations nationwide to engage families, improve systems of care, strengthen organizational infrastructure, and deliver high-quality services to CYSHCN and their families.

In 2025, Family Voices shared expertise through:

- Providing high-quality training and technical assistance
- Developing leadership within partner organizations
- Strengthening data, reporting, and evaluation capacity
- Facilitating peer mentorship and collaborative learning
- Expanding systems knowledge through national and international presentations
- Growing cross-sector partnerships and collaborative work

Our Network

A **Family Voices Affiliate Organization (FVAO)** is a statewide/territory-wide/tribal, parent/family-led non-profit organization, with a Board composed of a majority of family members of CYSHCN, that meets the requirements of an FVAO and works to advance the mission, vision, and principles of Family Voices. FVAOs are a critical part of our collective effort to keep families at the center of children's health care.

Family Voices provides technical assistance to the **Family-to-Family Health Information Centers (F2Fs)** through the Family Engagement and Leadership in Systems of Care cooperative agreement, funded through 2028 by the Health Resources and Services Administration (HRSA) Maternal Child Health Bureau. F2Fs are family-led organizations that support families of children and youth with special health care needs (CYSHCN).

Through these networks, Family Voices reaches families in all 50 states, 5 US territories and 3 tribal nations.

Our staff and Board of Directors are committed to our mission and work together to broaden our impact.

Our Staff

Armelle Casau, Director of Programs & Partnerships

Lauren Cavanagh, Senior Accounting Manager

Suzanne Farris, Program Operations Manager

Colleen Hanna, Grants, Donations, and Contracts Coordinator

Andrea Li, Project Director

Nikki Montgomery, Director of Strategy & Communications

Ashlee Richey, Director of Digital Operations

Roseani Sánchez, Project Director

Allysa Ware, Executive Director

Wesley Wei, Policy Manager

Ian Whitney, Digital Operations Manager

Our Board of Directors

Dennis Kuo, President

Susan Hill, Vice President

Amy Houtrow, Treasurer

Carolyn Allshouse, Secretary

Nanfi Lubogo, Past President

Emily Bill

Rosalba Calleros

Janis Connallon

Robert Duncan

Delia Hasberry

Hazel James Tohe

Stephanie Manfredo

Edwin Simpser

Jenna Weglarz-Ward



Our Family and Youth Organizational Advisory Committee

In 2025, Family Voices initiated our first organization-wide Family and Youth Advisory Committee. The committee plays a key role in shaping our work and ensuring that our strategic goals reflect and honor the communities we serve. Each of our advisory committee members is a parent, caregiver, or family member of a child/young adult who has a disability and/or identifies as a youth, young adult, or lived experience partner with a disability.

Committee members share their perspectives and priorities for evaluating the impact of our work, while strengthening our organization's ability to define and address systemic barriers and biases impacting the quality of life and well-being for CYSHCN and their families.

Our inaugural Family and Youth Organizational Advisory Committee members are:

Ruchi Agarwal
Jennifer Banna
Yolanda Brannon
Elvira Dennison
Jessica Edgar
Sophie Greer
Nancy Netherland
Rodney Newman
Rajon Mahones Ospina
Shannon O'Hara Wiora
Elgin Thrower Jr
Felica Turner-Walton



Our Programs

The collective impact of Family Voices' programs is a nationally coordinated effort that advances family engagement as a core driver of equitable healthcare systems for children and youth with special health care needs (CYSHCN). Family Voices' program work focuses on two key areas: Research & Implementation and Integrated Systems.



Research & Implementation

Family Voices' research and implementation projects focus on using proven youth and family engagement strategies to improve the outcomes and systems of care for all children and families, especially those with special health care needs and disabilities. We engage and support youth and families to ensure that research translates to meaningful results and changes that matter to children and families.



Integrated Systems

Family Voices' integrated systems work engages youth and families with the many systems needed to support their health and well-being across the lifespan. By supporting sustainable connections among systems and families, systems of care become more responsive to the needs of children and families – from early childhood to the transition to adult health care, and every stage in between.

Our Areas of Influence and Expertise

- Family engagement and leadership in systems of care
- Family engagement and leadership in research
- Transition from pediatric to adult health care
- Family navigation
- Access to care and services
- Language access and accessibility
- Early childhood systems
- Disability and neurodiversity
- Peer mentorship for families of CYSHCN
- Telehealth
- Health literacy

29

In 2025, Family Voices led or partnered in 29 projects related to child and adolescent health, research, and special health care needs.

Through our programs, Family Voices:

- Consistently builds the skills, knowledge, and structures required to promote authentic family engagement in healthcare systems and research.
- Strengthens the capacity of families, youth, providers, and networks nationwide to participate meaningfully in improving systems of care.
- Meaningfully reduces systemic inequities—including ableism, racism, and language barriers—ensuring CYSHCN and their families are included, heard, and supported.
- Models innovation for the field by developing new tools, strengthening evaluation practices, and helping partners embed family engagement scientifically and strategically.



98%

Among our webinar feedback survey respondents, 98% reported that technical assistance from Family Voices helped their organization implement best practices and strategies to increase family engagement.

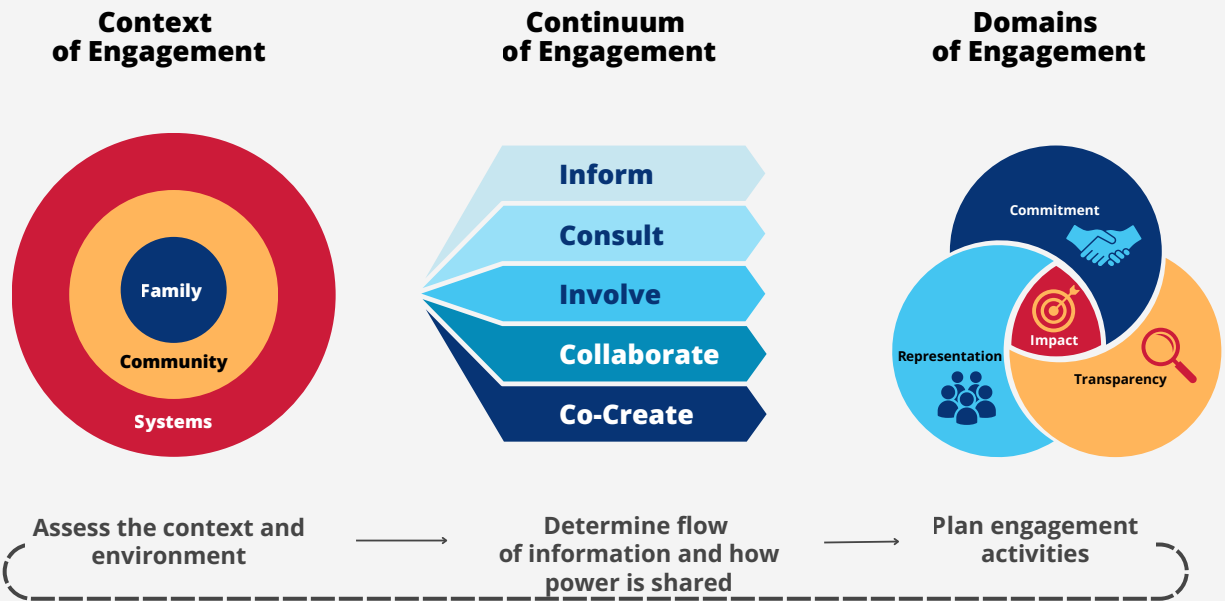
Our Evidence-Based Framework for Youth and Family Engagement

In 2025, Family Voices finalized our evidence-based framework for youth and family engagement. This structure guides our work and ensures consistency and quality in family engagement across settings and systems.

Family engagement is an intentional partnership between families, youth, and health-related service providers across the systems of care. Family engagement is grounded in mutual respect, shared decision-making, and the recognition of the unique expertise that families and youth bring through their lived experiences.

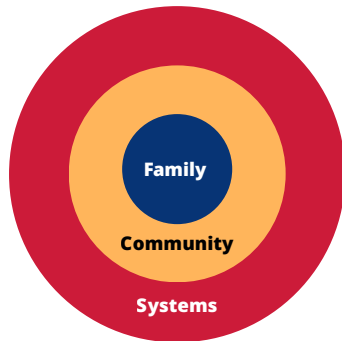
Our evidence-based framework for youth and family engagement includes three main areas of focus:

- The context and environment for engagement
- The flow of information and how power is shared
- Planning, assessing and improving engagement in four domains



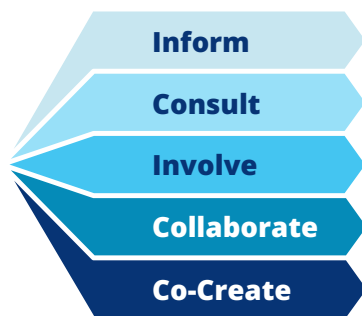
Read about the framework for youth and family engagement at familyvoices.org/familyengagement.

A Closer Look at the Framework



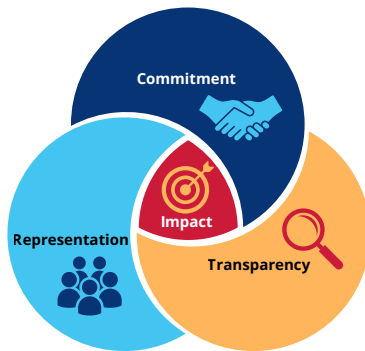
Context of Engagement

The context and environment for engagement includes the readiness of the team engaging youth and families and the people or context their engagement is intended to impact (Bennett et al., 2020). We assess teams to understand whether they are ready to engage youth and families in meaningful ways, and we provide technical assistance to meet each team's unique needs to prepare for engagement. The assessments and technical assistance we provide are tailored to the setting and context in which the team operates.



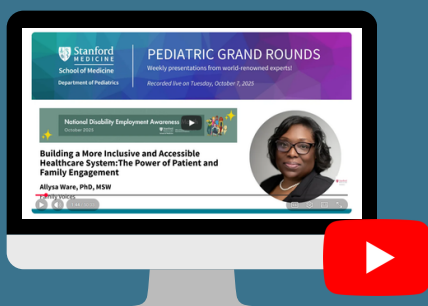
Continuum of Engagement

Next, we look at how information and power are shared in each team's context. The flow of information and the decision-making power both have a role in how effectively youth and families are engaged (Carman and Workman, 2017). We help organizations and teams assess and reorganize communication on each level of the continuum and share power to maximize youth and family participation and minimize harm.



Domains of Engagement

Finally, we help each team plan, assess and improve their engagement in four specific domains: commitment, transparency, representation and impact (Hoover et al., 2018). Each domain represents a core element of effective engagement that can be improved over time. Our training and assessment processes help organizations understand how effectively they are employing each domain in an organization or initiative and set specific goals in each domain.

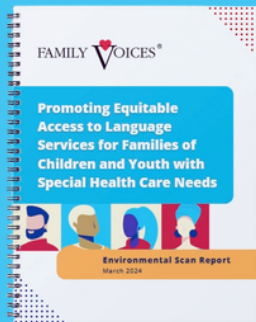


[Watch Dr. Ware's discussion](#) on the framework in her presentation for Stanford University Pediatric Grand Rounds, "Building a More Inclusive and Accessible Healthcare System: The Power of Patient & Family Engagement."

Project Highlight

In 2025, Family Voices concluded our work on **Promoting Access to Language Services for Families of Children and Youth with Special Health Care Needs** (CYSHCN). Funded by the Office of Minority Health, this project increased the quality and use of language access services in the health care setting.

Family Voices led the project, with partnership from the American Academy of Pediatrics, the Children’s Hospital Association, and the National Association of Community Health Workers. Materials from this work are available at familyvoices.org/languageaccess.



Our work on this project began with an environmental scan to assess the state of language access services in pediatric health care, gathering input from more than 600 individuals, including families, health care providers, interpreters, and community partners. The findings were used to inform program activities, training content and educational resources, all to increase awareness, understanding, and use of language access services in health care settings for families of CYSHCN whose preferred language is not English.

80

original language access tools and resources were developed

Over the three years of the project, project leaders, with input from the advisory committee and Cultural Responsiveness Committee, developed 80 unique resources, including tip sheets, videos, training curricula, toolkits, data reports, and other practical materials tailored to a range of audiences and translated into multiple languages.



67K

youth, families, community health workers, and health care providers received education on language access

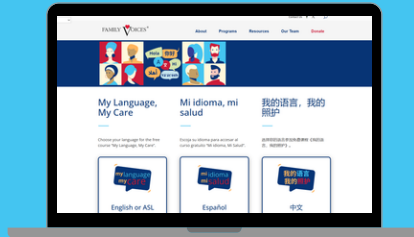
Collectively, the project’s resources were disseminated to more than 67,000 individuals through multiple channels, including the Family Voices network, partner organizations, the project website, and social media platforms.

A cornerstone of the project’s training outcomes was “My Language, My Care,” a free online course designed to increase awareness of language access rights and use of language access services among families whose preferred language is not English.

Available in English, Spanish, Chinese, and American Sign Language (ASL), the course includes a six-module curriculum for families and a three-module curriculum for community health workers, along with supplemental materials. The course will remain on our website at familyvoices.org/mylanguageandmycare.

4

languages offered for the free online training module, “My Language, My Care”



“

“This course is truly a transformative experience, and I highly recommend it to everyone! It elevates your skills and deepens your understanding of language diversity, cultural nuances, and unique perspectives. It’s an opportunity to grow both personally and professionally in ways you won’t expect!”

– Aya Ali



100%

All participants surveyed agreed or strongly agreed that the **My Language, My Care** training helped them with seeking and/or advocating for quality language services.

Engaging Youth and Families

\$142,000

In 2025, Family Voices provided \$142,000 in compensation to youth and family leaders from across the US, territories and tribal nations.

Compensating youth and family leaders is central to our commitment to ensuring equitable engagement in health care transformation initiatives. By providing compensation for youth and families, our work helps to remove barriers to participation, while honoring and valuing lived experience as expertise.

Along with compensating youth and families in our work, we support our partners and funders in developing policies for sustainable funding for family engagement. This commitment aligns with the technical assistance and training we provide throughout the field and is based on the core domains of our evidence-based framework for family engagement.

526

In 2025, Family Voices provided more than 500 individual stipends to youth and family leaders engaged in our work to transform systems of care.

Each of the 500+ stipends we award represents a youth or family leader who is actively involved in or leading work to change the systems that serve children and youth with special health care needs and disabilities.

From focus groups and interviews to advisory committees and governance boards, the voices of families are shaping organizations, policies and systems.

Resources to Support Youth and Family Engagement

Family Voices continued the expansion of our resource library in 2025, with hundreds of free, downloadable resources on many health-related topics that are relevant to organizations serving families of children with special health care needs and disabilities. Our approach to developing resources includes our commitment to:

- **Plain language** that support health literacy and health equity
- **Language access** that includes Spanish translation of many resources, with other languages available as well
- **Multiple formats** – from print to audio and video – to meet the literacy and access needs of families

Family Voices' library of resources can help health professionals improve their knowledge and practice around:

- Evidence-based practices for family engagement
- Family/professional partnerships
- Specific health conditions and health-related topics, like genetic conditions, Medicaid, and telehealth, among many others.



Visit familyvoices.org/resources to search our library.



Policy & Advocacy

Family Voices' policy and advocacy work in 2025 focused on strengthening partnerships, shaping national policy priorities, and expanding accessible policy resources to advance equitable health care for children and youth with special health care needs.

Family Voices engaged in extensive federal policy and advocacy work, including attending regional convenings, hosting listening sessions, and meeting with national youth-led, disability, and advocacy organizations to strengthen partnerships and align strategies. Activities included ongoing collaboration with groups such as Students Engaged in Advancing Texas (SEAT), Youth MOVE, Youth as Self-Advocates (YASA), Generation Patient, and various Family-to-Family organizations to share federal policy updates, co-develop briefs, plan trainings, and gather lived-experience input to shape policy priorities.

Our Policy Manager presented at national conferences, participated in coalition meetings, and partnered with organizations like Invariant, Georgetown Center for Children and Families, Team Select, and Manatt Health to advance policy on Medicaid, family caregiving models, and CYSHCN-focused initiatives.



Executive Director, Dr. Allysa Ware (center) is joined by Policy Manager Wesley Wei (left) and former Chief of Staff Maggie Liu (right) on Capitol Hill to advocate for legislation that supports the Family-to-Family Health Information Centers.



Policy Education Materials

A large portion of the year's work in policy centered on producing accessible policy materials and guiding strategic policy direction. This included developing and translating plain-language briefs, drafting and releasing the 2025–2026 strategic policy priorities, piloting policy outcomes frameworks with staff, and creating new resources on family engagement and communication about policy changes. Listening sessions across constituencies helped refine priorities, while new collaborations supported cross-sector learning.



Supporting Legislation

Family Voices signed onto many letters of support and joint statements across a wide range of federal issues affecting children, families, people with disabilities, and the broader health care landscape. These included letters on Medicaid protections, mental health legislation, disability rights, transportation accessibility, maternal and child health funding, and responses to federal administrative restructuring such as actions related to the Richardson Waiver and HHS reorganization. Collectively, these sign-ons reflect sustained advocacy to protect health coverage, improve access to care, uphold disability rights, and support federal programs serving CYSHCN and their families.



Learn more about our policy initiatives and agenda at familyvoices.org/publicpolicy.

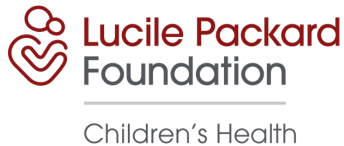
Our Partners & Funders

In 2025, Family Voices partnered with many organizations and initiatives to advance health care improvement and increase youth and family engagement. Our partners included:

- AcademyHealth
- Administration for Community Living
- Advocacy without Borders
- Altarum
- American Academy of Pediatrics
- Association of Maternal & Child Health Programs
- The Beryl Institute
- Boston University Center for Innovation in Social Work and Health
- Center for Health Care Strategies
- Center for the Study of Social Policy
- Child & Adolescent Health Measurement Initiative
- Children's Hospital Association
- Cornell University
- Duke University
- Georgetown Center for Children and Families
- Help Me Grow
- Life Course Translational Research Network (LCT-RN)
- Lucile Packard Foundation for Children's Health
- Manatt Health
- Maternal & Child Health Bureau
- The National Academies of Sciences, Engineering, and Medicine
- National Alliance to Advance Adolescent Health (Got Transition)
- National Association of Community Health Workers
- National Institutes of Health
- National Institute for Children's Health Quality (NICHQ)
- National Maternal and Child Health Workforce Development Center
- NORC at the University of Chicago
- Nurture Connection
- NYU Langone Health
- Office of Minority Health
- Patient-Centered Outcomes Research Institute
- Pediatric Supporting Parents
- Rutgers University
- SPAN Parent Advocacy Network
- Systems & Policy Research Network
- Team Select
- UMKC Institute for Human Development
- United Healthcare
- University Hospitals
- University of Rhode Island
- Waisman Center
- WITH Foundation
- W.K. Kellogg Foundation
- Youth as Self-Advocates
- ZERO TO THREE

Funder Spotlight

Family Voices has a strategic goal of diversifying our funding sources to include more unrestricted funding. Two key partnerships helped us move this goal forward in 2025.



Lucile Packard Foundation for Children's Health

In 2025, Family Voices received continued general operating funding from Lucile Packard Foundation for Children's Health. The funding supports our work to meet our strategic goals and build our capacity to achieve our mission. This funding has supported enhancements to our organizational evaluation and data collection, expansion and revision of materials for the Family Engagement in Systems Assessment Tools (FESAT), policy and advocacy, and the development of our technical assistance and membership models.



WITH Foundation

WITH Foundation entered a strategic partnership with Family Voices to build on our work to support the health of individuals with disabilities, specifically from underserved communities, in the transition to adult health care. Through this partnership, we have focused our efforts on addressing the needs of youth with intellectual and developmental disabilities in the juvenile justice system and on Black autistic girls and women, populations that experience tremendous disparities in care and outcomes.

Financial Highlights

Family Voices generated \$4.5 million in total revenue for fiscal year 2024-25, with grants comprising the largest revenue source at 90% of total income. Our grant revenue demonstrates continued strong support from foundation and government funders.

Direct public support showed remarkable growth, increasing from \$56,128 in FY 2022-23 to \$182,063 in FY 2024-25. This 224% increase in direct public support reflects expanded donor engagement and community support.

Total expenses of \$3.9 million in FY 2024-2025 were primarily allocated to personnel (\$2.0 million) and direct program costs (\$1.4 million), maintaining our commitment to mission-driven service delivery.

Family Voices achieved a net surplus of \$615,325 for FY 2024-25, marking a significant turnaround from prior year deficits and reflecting improved financial sustainability.

Over the three-year period, Family Voices delivered over \$11.3 million in programmatic impact while maintaining strong fiscal stewardship and transparent financial practices aligned with nonprofit best practices.

Prepared for Family Voices 2025 Annual Report | Data Source: Statement of Activity FY 2022-2025



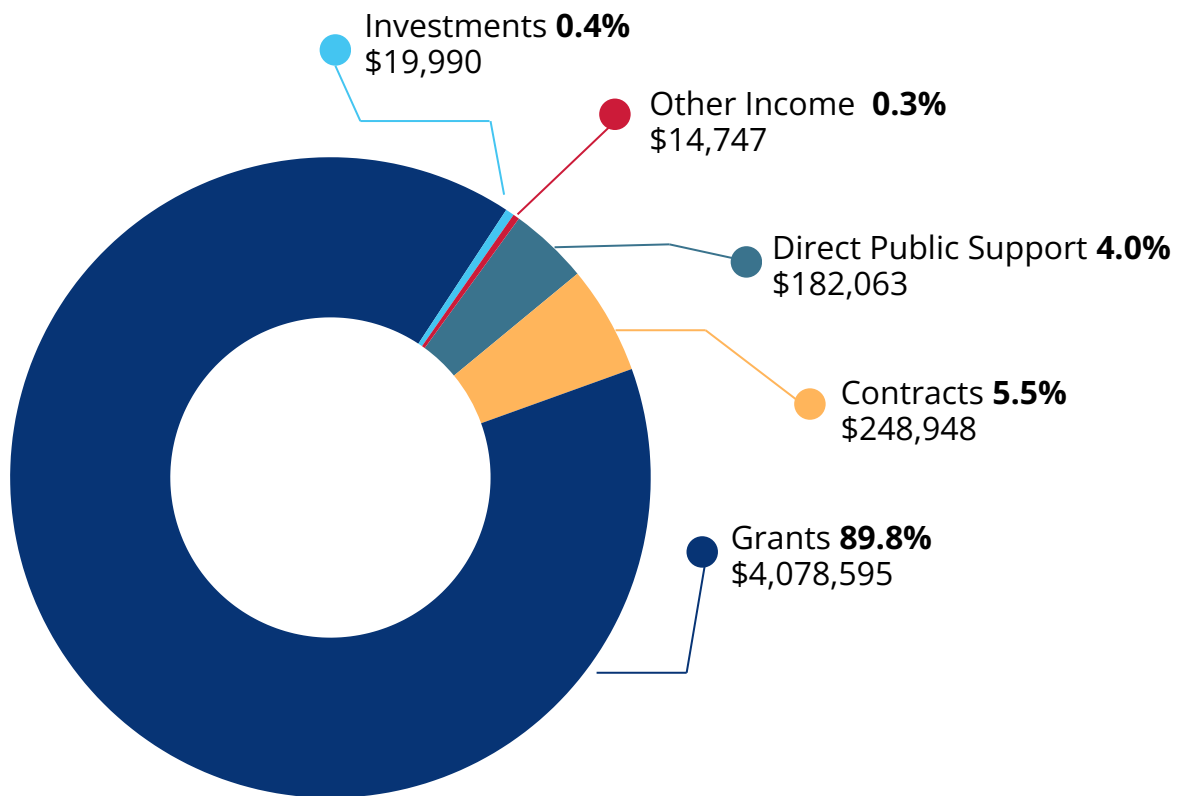
Family Voices has a four-star Charity Navigator rating, which demonstrates our top-tier accountability, finance performance, and healthy governance practices.



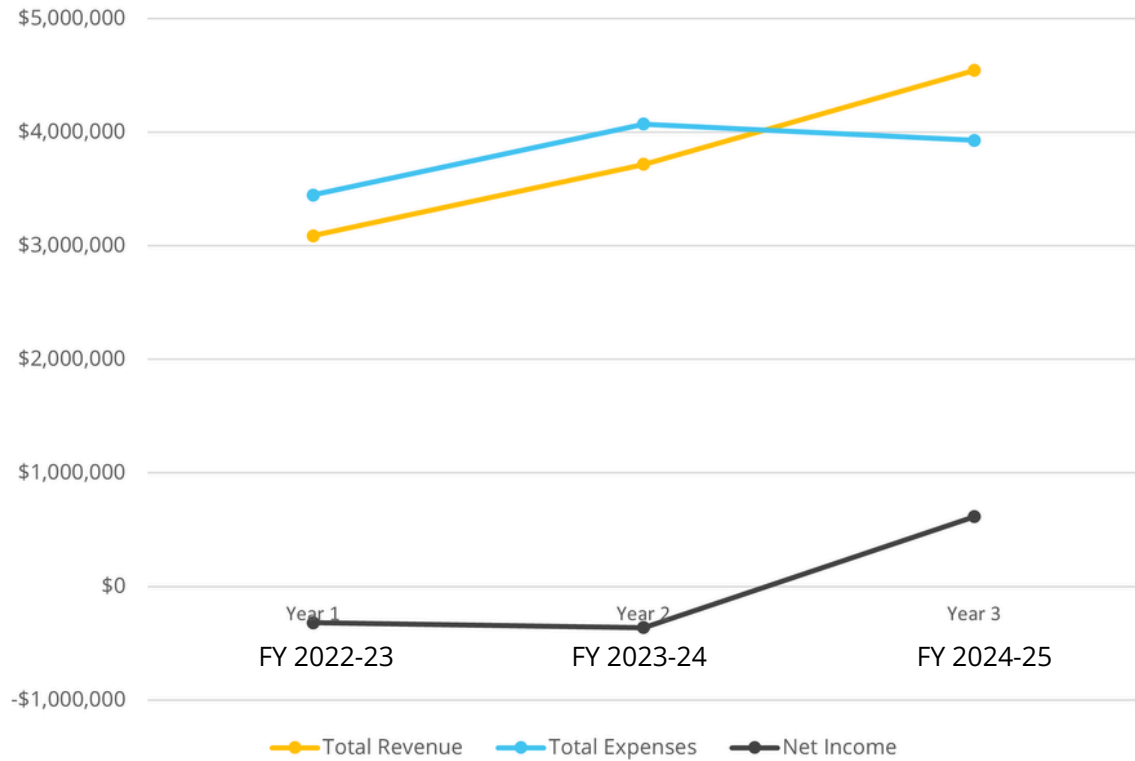
Key Financial Metrics

| Metric | FY 2022-23 | FY 2023-24 | FY 2024-25 |
|--------------------------|-------------|-------------|-------------|
| Total Revenue | \$3,088,540 | \$3,716,834 | \$4,544,344 |
| Total Expenses | \$3,446,562 | \$4,072,124 | \$3,929,019 |
| Net Income | -\$319,006 | -\$362,778 | \$615,325 |
| Program Efficiency Ratio | 49.3% | 36.7% | 34.9% |

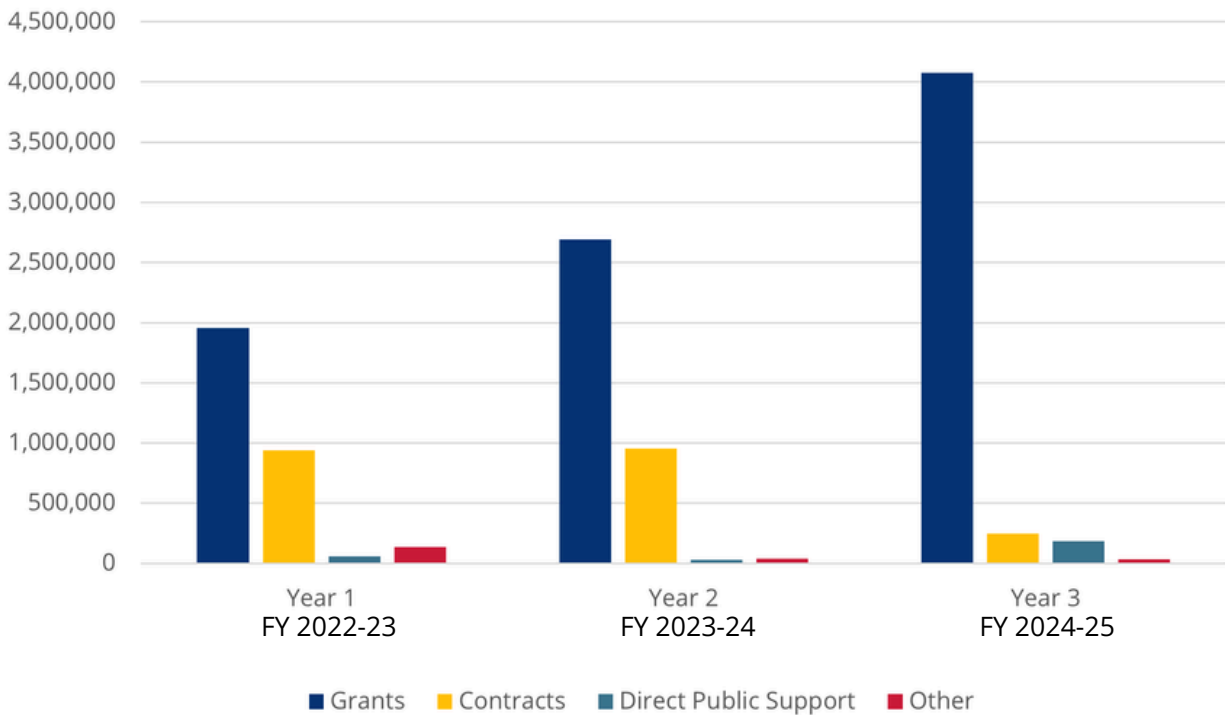
FY2024-25 Revenue Sources



Revenue vs. Expenses vs. Net Income 3-Year Trend



Revenue by Source 3-Year Comparison





*Improving children's health,
especially those with special
health care needs and
disabilities*

One in four children in the US has special health care needs, according to the National Survey of Children's Health. Unfortunately, children with special health care needs have less access to the coordinated health care services that help them to thrive. Our work at Family Voices closes that gap by improving the systems that serve children with special health care needs.

With the support of our generous donors, Dr. David Nichols and Mayme Boyd, Family Voices achieved a record-breaking fundraising year through the Close the Gap Campaign, which matched \$30,000 in campaign donations!



“ Family Voices plays a singular and critical role as a national network that helps these families achieve the very best health and education for their children with special needs. I hope this challenge grant will inspire others to support Family Voices as it spreads technical knowledge, amplifies the voices, and injects hope for children and youth with special health care needs to live their best lives. ”

David G. Nichols, M.D., M.B.A.

Emeritus President and Chief Executive Officer, The American Board of Pediatrics
Emeritus Professor of Anesthesiology, Critical Care Medicine, and Pediatrics,
The Johns Hopkins University School of Medicine

familyvoices.org/closethegap

2025 Close the Gap Campaign Results

40

individual donors

\$314

average donation
amount for
individual donors

\$30,599

With the support of our donors,
Family Voices surpassed the
match goal of \$30,000!

Thank you to our donors!



2025 Partner Level Donors

Stephen Anderson
Christina Baker
Vaishnavi Bawa
Joni Bruce
Leslie Carroll
Christopher Case
Anna Cyr
Robert Duncan
Ben Edwards
Kunika Gupta
Eric Haugen
Patricia Heu
Amy Houtrow
Mike Kelly
Soheila Korourian
Joshua Kotler
Dennis Kuo
Claire Lenker
Sharon Lewis

Cristina Malone
Patrick Malone
Cindy Mann
Jill McCormick
Max Meyerhoff
Maxwell Mitchell
Nancy Murphy
David Nichols
Amy Ossman
James Perrin
Rylin Rogers
Lisa Sanderson
Ellen Schwalenstocker
Brooke Strawn
Melissa Vickers
Deborah Walker
Nora Wells
Peters Willson



2026 Family Voices Leadership Conference



The 2026 Family Voices Leadership Conference will be held on April 15-16, 2026, with pre-conference trainings on April 13-14. The virtual conference will welcome hundreds of youth and family leaders, patient advisors and advocates, physicians and health care professionals, and policy makers. Dr. Nakela Cook, Executive Director of the Patient-Centered Outcomes Research Institute, will deliver the keynote speech. An awards ceremony will recognize excellence in family engagement and care system transformation.

Learn more at familyvoices.org/FVLC2026.

Conference Sponsors



United Healthcare
Platinum Sponsor



W.K. Kellogg Foundation
Silver Sponsor



SPAN Parent Advocacy Network
with Diana MTK Autin and W. Keith Hefner
Health Equity Sponsor



Manatt
Policy Sponsor



Lucile Packard Foundation for Children's Health
Bronze Sponsor



Children's Hospital Association
Bronze Sponsor

American Academy of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN®

American Academy of Pediatrics
Supporter Sponsor



Association of Maternal & Child Health Programs
Supporter Sponsor



Dr. Dennis Kuo
Supporter Sponsor



How to Support Our Mission



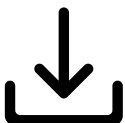
Sign up for our mailing lists to learn more about what is happening nationally for children and youth with special health care needs and how Family Voices is leading the way.



Support Family Voices for years to come by including us in your estate plans. A planned gift, such as naming Family Voices in your will or as a beneficiary, helps ensure children and families continue to receive the support they need. To learn more, read our [Estate Planning Information Sheet](#).



Follow us on social media, where we share information about issues and outcomes that are important to children and families.



Download and share resources from our website to support families and improve systems of care.



Make a gift to the Close the Gap Campaign to help us reach our 2026 goal of \$30,000!

