



FAMILY VOICES of California

17th Annual

HEALTH SUMMIT & LEGISLATIVE DAY

Sunday, March 10 - Tuesday, March 12, 2019

www.familyvoicesofca.org

Holiday Inn Downtown
300 J Street | Sacramento



About Us

FAMILY VOICES of California

Who We Are

Family Voices of California is a statewide collaborative of parent-run centers working to ensure quality health care for children and youth with special health care needs and disabilities.

Our Vision

- The voice of Families
- The vision of quality health care
- The future for children and youth with special health care needs

Our Work

- Policy: We monitor legislation, regulation, and policies impacting children with special health care needs and disabilities, and collaborate with advocacy partners to include the voice of families.
- Project Leadership: A training curriculum designed to help family members develop skills and tools to engage at all levels of decision making and public policy advocacy.
- Health Summit & Legislative Day: An annual convening of families, youth, advocates, state and local agencies, and legislators and staff.
- Whole Child Model: A partnership with the California Department of Health Care Services to inform and educate families and communities about the California Children's Services transition to the Whole Child Model. Toll free information: 1-888-387-0393.



www.familyvoicesofca.org
[@FamilyVoicesCA](https://twitter.com/FamilyVoicesCA)

Summit Objectives

- | Provide information about policies, legislation, proposals, and other efforts affecting health programs for children and youth with special health care needs and disabilities
- | Build capacity and skills for families to advocate for health systems improvements
- | Foster relationships among families, providers, advocates, and decisionmakers
- | Engage families to impact decision makers at all levels of community and government where health care decision making occurs

We envision a world where our children's health care is self-determined and family centered, and quality health care is the norm. Our work today is one more step to impact the policies and procedures to make that vision a reality.



Sunday, March 10

Schedule

Advocacy and Leadership Strategies for Families

2:00 pm | Registration

2:30 pm | Moving from Individual to Systems Advocacy

Elaine Linn: Project Leadership Manager, Family Voices of California

3:15 pm | Storytelling for Impact

Group Activity

4:00 pm | Enhancing Social Media through Advocacy

Kaitlin Perry: Account Manager, Perry Communications Group, Inc.

4:45 pm | Preparing for Legislative Visits

Regional Team Planning

5:30 pm | Closing

What You Can Do

| Stay Informed

- Subscribe to e-newsletters
- Follow social media
- Participate in webinars
- Attend meetings and hearings

| Build Relationships

- Get to know your elected officials
- Review their Websites
- Subscribe to their newsletters
- Attend Town Halls
- Schedule Capitol and district meetings

| Engage

- Attend a Project Leadership training
- Share your story
- Respond to Action Alerts – Call, email, post
- Attend hearings, meetings, rallies, etc.
- Give public comment – written or verbal
- Serve on a board or committee
- Organize or participate in a campaign
- Use social media for advocacy

| Find Your State Legislators: <http://findyourrep.legislature.ca.gov>

| Find Your Congressional Representatives: www.house.gov/htbin/findrep

| Sign Up for Family Voices of California's News Digest: www.familyvoicesofca.org

Want to get more involved in health systems advocacy? We can help. Contact Elizabeth Mercado at emercado@familyvoicesofca.org.



Monday March 11

Schedule

Health Summit

7:30 am | Registration and Continental Breakfast

8:30 am | Welcome & Overview

- Yvette Baptiste: Executive Director, Eastern Los Angeles Family Resource Center
- Katie Hornberger: Director, Office of Clients' Rights Advocacy, Disability Rights California
- Kausha King: Parent, Family Voices of California Project Leadership Graduate

9:00 am | What Happens in Washington Doesn't Stay in Washington

Anthony Wright: Executive Director, Health Access

9:45 am | Family Empowerment for Health Systems Change

Elaine Linn: Project Leadership Manager, Family Voices of California

10:00 am | Break & Youth Track Begins (Calaveras Room)

10:15 am | How Does California's Health System "Rate?"

Moderator - Kelly Hardy: Senior Director, Health & Research, Children Now

- Jennifer Kent: Director, California Department of Health Care Services
- Jordan Lindsey: Executive Director, The Arc of California
- Noemi Spinazzi, MD, FAAP: Benioff Children's Hospital Oakland, UCSF School of Medicine
- Kimber Rice: Parent, Family Voices of California Project Leadership Graduate; Family & Community Engagement, San Juan Unified School District

11:45 am | Lunch

12:45 pm | Envisioning Better Brain Health

Moderator - Anne Hall: Parent, Family Voices of California Project Leadership Graduate

- Alex Briscoe: Principal, The Children's Trust
- Kim Lewis: Managing Attorney, National Health Law Program
- Adrienne Shilton: Government Affairs Director, The Steinberg Institute

1:45 pm | Transition to Breakouts



Monday March 11

Schedule

Health Summit

1:55 pm | Breakout Session 1

Overcoming Barriers to Treatment and Care

- Kim Lewis: Managing Attorney, National Health Law Program
- Liz Helms: President & CEO, California Chronic Care Coalition

Health Care in the School Setting

- Carly Munson: Litigation Counsel, Disability Rights California
- Pamela Kahn: President-Elect, California School Nurses Organization

CCS and the Whole Child Model

- Ali Barclay: Outreach Education Manager, Family Voices of California
- Laurie Soman: Director, Children's Regional Integrated Service System; Senior Policy Analyst, Lucile Packard Children's Hospital

2:55 pm | Transition to Breakout Session 2

3:05 pm | Breakout Sessions Repeated

4:15 pm | Keynote Presentation

- Assemblymember Jim Frazier: 11th Assembly District

4:45 pm | Closing Remarks, Legislative Day Information, Evaluations

- Katie Hornberger
- Kausha King

Youth Track | Calaveras Room

PRESENTER

- Brittnee Gillespie: Disability Rights California

10:15 am | Introductions & Objectives

10:20 am | Voting Rights

11:00 am | Hands Off My Money

11:45 am | Return to Ballroom for Lunch

12:45 pm | Return to Calaveras Room

Emergency Preparedness

1:55 pm | Bingo

3:05 pm | Breakout Session 2

Choose one breakout topic from above

4:05 pm | Return to Ballroom for Keynote Presentation



Tuesday, March 12

Schedule

Legislative Day

6:30 am | Continental Breakfast

Holiday Inn Downtown (300 J Street, Sacramento)

7:30 am | Hotel Checkout and Travel to Legislative Briefing

California Dental Association (1201 K Street, Sacramento)

Check in at the security desk in the lobby

8:30 am | Making the Most of Your Legislative Visit

California Dental Association

- Carl London: Partner, London & Gonzalez Advocacy

10:00 am | Legislative Visits

State Capitol (11th & L Streets, Sacramento)

Enter security checkpoint on L Street between 10th & 11th Streets

Special Thanks to the 2019 Summit Advisory Committee

- Catherine Blakemore – Disability Rights California
- Angela Blanchard – Political Solutions
- Dena Davis – Parent Advocate
- Allison Gray – Lucile Packard Foundation for Children's Health
- Anne Hall – Parent Advocate
- Kelly Hardy – Children Now
- Lynda Karl – Parent, Leadership Education in Neurodevelopmental & Related Disabilities (LEND) Graduate
- Erin Kelly – Children's Specialty Care Coalition
- Kausha King – Parent Advocate
- Grace LeRoy – Parent Advocate
- Mira Morton – California Children's Hospital Association
- Katie Layton – Children's Specialty Care Coalition
- Kathryn Smith – Children's Hospital Los Angeles
- Laurie Soman – Children's Regional Integrated Service System; Lucile Packard Children's Hospital
- Family Voices of California Executive Council Member Agencies



Key Issues

Ensuring Access to Care, Treatment, and Services

Overview

| Family Voices of California (FVCA) is a collaborative of parent-run centers working to ensure quality health care for Children and Youth with Special Health Care Needs (CYSHCN) and disabilities.

Quick Facts

| CYSHCN are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required for children generally.

| 52% of children with special health care needs are covered by Medi-Cal.

| Nearly 20% of children under age 18 have a special health care need.

| 42.4% of CYSHCN were reported to have an emotional, developmental, or behavioral issue.

| The systems serving California's CYSHCN are failing to meet standards for access to care, quality of care, family-centered care, and family satisfaction.

| Families caring for CYSHCN experience more significant financial and caregiving demands.

| Families may experience financial problems from multiple and costly medications, equipment, therapies, or specialty appointments, and loss of income from taking time off work to care for CYSHCN.

Objectives | Priorities

| **California Children's Services (CCS) program standards must remain current.** The state, counties, health plans, and providers should work together to maintain high quality, evidence-based initiatives to provide medically complex children with the care they need, when and where they need it. Programs must be closely monitored and evaluated as the state transitions specialty care from fee for service to managed care (i.e., in Whole Child Model counties).

| **Children with Special Health Care Needs must have timely access to quality primary and specialty care,** medications, therapies, equipment, and related services. California's per capita Medi-Cal expenditures are the lowest in the nation, impacting the number of providers able to remain in networks. Provider rates must reflect the cost of service provision to maintain and expand networks and ensure that CYSHCN have access to the highest quality and most innovative treatments.

| **Families must be able to participate at all levels of government and community where health care decisions are made.** Families are on the front lines of caring for medically complex children, and only they can share authentic experiences about the impact of health care funding and policies. It is critical that decision makers hear directly from families as they deliberate policy changes, and that families have input and a decision-making role.

| **Children and youth with special health care needs and disabilities must have access to high quality community based services, providers, and programs.** The system that provides services to people with intellectual and developmental disabilities is in crisis due to inadequate rates causing program closures, waiting lists, and staff shortages. Consumers are going without necessary services because providers can't offer services at the authorized rates. An 8% rate increase would provide a down payment to stabilize the system, allow California to access nearly \$200 million in federal matching funds, ensure compliance with federal regulations, and fulfill its commitment to the more than 330,000 individuals with disabilities.



Thanks to Our Sponsors

LEADERSHIP



Lucile Packard Foundation
for Children's Health

SPIRIT



CALIFORNIA
CHILDREN'S
HOSPITAL
ASSOCIATION

PARTNER



Lucile Packard
Children's Hospital
Stanford



McCune
FOUNDATION

COLLABORATION



HOPE



American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™
American Academy of Pediatrics, California

