



16th Annual Health Summit and Legislative Day

February 26-27, 2018

FAMILY  VOICES
of California

familyvoicesofca.org

ABOUT FAMILY VOICES OF CALIFORNIA

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

Mission

FVCA builds the capacity of parent centers throughout California to provide families with the information and support they need to make informed decisions about the health care of their children. FVCA provides information and a forum for parent centers and families to advocate for improved public and private policies, builds partnerships between professionals and families, and serves as a vital resource on health care.

Vision

The voice of families.

The vision of quality health care.

The future for children and youth with special health care needs.

Council Member Agencies

- Alpha Resource Center - Santa Barbara County
- Eastern Los Angeles Family Resource Center - Los Angeles County
- Family Resource Network - Alameda County
- Rowell Family Empowerment Center - Butte, Glenn, Shasta, Tehama, and Trinity Counties
- Support for Families of Children with Disabilities - San Francisco County

Staff

Pip Marks - Project Director

Elaine Linn - Training Manager

Lilian Ansari - Family Engagement Manager

About Project Leadership

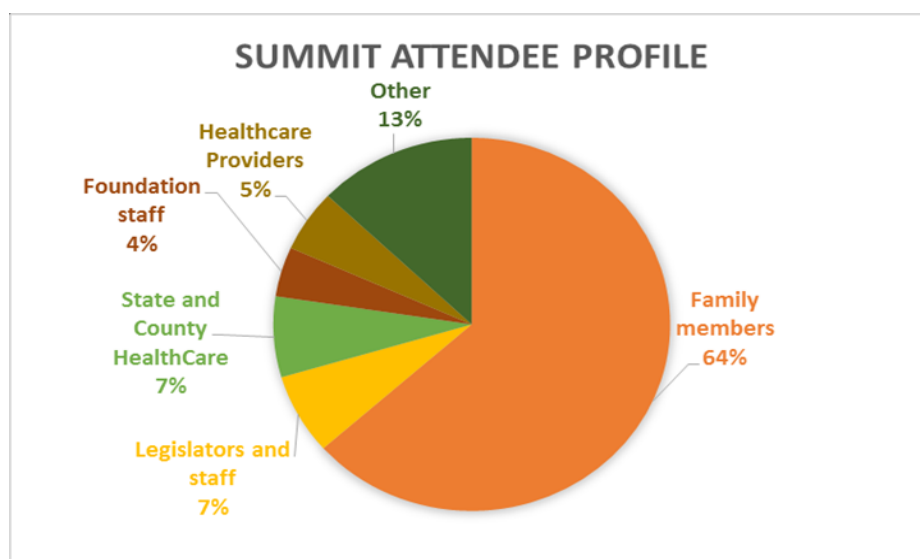
Project Leadership is a parent advocacy training program designed to increase the number of family members of children with special health care needs who are prepared and supported to become advocates for health care policy and service improvements. The curriculum introduces families to the nuts and bolts of advocacy in a seven-session training series. Project Leadership is funded through a grant from the Lucile Packard Foundation for Children's Health.

"It truly helped me understand the impact a parent like me can have."

2018 HEALTH SUMMIT

February 26, 2018

This year marked Family Voices of California's (FVCA) 16th annual Health Summit in Sacramento, bringing together more than 185 people representing counties spanning from Humboldt in the north, to San Diego in the south. Attendees included 118 family members who were joined by representatives of state and local agencies, foundations, and health plans, as well as health care providers, and legislators and staff. Long before the event, the FVCA 2018 Summit Advisory Committee, made up of families and professionals, worked together to plan the day. Advisory Committee members are listed on page 13.



Summit Objectives

- Provide a clear understanding of the proposed changes to Medicaid/Medi-Cal programs;
- Discuss opportunities to improve mental health treatment and services;
- Highlight the importance of meaningful family engagement; and
- Convey strategies to impact decision makers at all levels of healthcare and health policy.

Family Sponsorships

Thanks to the support of generous sponsors, FVCA provided breakfast and lunch for all attendees, and full sponsorship for 30 families, including meals, childcare, lodging, and travel. Sponsored families also participated in a networking dinner, and received a cash stipend to cover any additional expenses. Sponsors are on page 9.

PROGRAM OVERVIEW

General sessions featuring panel discussions and a breakout session with three options provided a forum for updates and information. Skills building was integrated into all aspects of the program. Families attending the Summit learned about key issues, their impact on CYSHCN, and how to present these issues to legislators.

Setting the Tone

This year's Summit featured many health care experts involved in policies affecting CYSHCN and their families. Speakers also included legislators, Project Leadership graduates and trainers, leaders of statewide advocacy organizations, and legislators. Beginning with Summit moderators Catherine Blakemore, executive director of Disability Rights California, and Kausha King, a parent and FVCA Project Leadership graduate, each speaker and presentation integrated Summit objectives and key messages to inform, educate, empower, and activate attendees to advocate for health system improvements.



**Assemblymember
Blanca Rubio;
Moderators
Catherine Blakemore
and Kausha King**

Panel discussion topics included:

- Medi-Cal
- Family Engagement
- Insights from Legislative Staff
- Mental Health

Breakout session provided the opportunity for more in-depth discussions about:

- The California Children's Services transition to the Whole Child Model
- Telehealth
- Working with Regional Centers

A full conference agenda is included on pages 10-11.

Speakers and Panels

The Summit opened with Assemblymember Blanca Rubio (48-Los Angeles) passionately imploring family members to use their voices to advocate and build relationships with providers and legislators. This was a message reinforced by luncheon keynote speaker Assemblyman Dr. Joaquin Arambula (31-Fresno), who shared his experiences as an

Emergency Room physician, and his understanding of the challenges in navigating health systems. Both reminded attendees of the power of personal stories, and the importance of using those stories to illustrate how legislation would impact families in day to day life.

Panel: Medicaid/Medi-Cal: Access to Services for Children and Youth with Special Health Care Needs in California

Scholars, state agency leaders, advocates, providers, and parents shared their perspectives on various aspects of Medi-Cal, including:

- State and federal programs, funding, policies, and services;
- The Governor's budget, including proposals to increase rates for home health providers;
- Various Medi-Cal waiver programs;
- Access to home-based services.



Senator Jim Beall (15-Santa Clara County – Mental Health Panel



Sara Eberhardt-Rios, CA Department of Health Care Services – Medi-Cal panel



Self advocates share their stories.

Panel: The Power of Family Engagement

A panel of professional and family advocates, along with a representative of the Lucile Packard Foundation for Children's Health, shared their diverse views on family engagement. All spoke about the benefits of engaging families to participate in the often lengthy decision making process at all levels of government and community, using data, personal experiences, and coalition building to integrate systems advocacy with individual advocacy.

Panel: Legislative Issues and Insights from Staff

California Children's Hospital President and CEO Ann-Louise Kuhns moderated a bi-partisan panel of legislative committee staffers who provided an overview of the legislative process and committee responsibilities. They also provided insights into upcoming policy issues affecting CYSHCN, and tips on how to maximize impact when advocating for issues.

Regional Discussion Groups

At the end of the day, attendees broke into small groups, organized by region, to reflect and process Summit content, and identify key points for legislative meetings the following day. Discussions were facilitated by regional leaders, and focused on current issues that could impact health care for CYSHCN.



Attendees from Orange County brainstorm during the regional discussion group session



Youth Track participants

Youth Track

Once again, this year's Summit featured a dedicated programming track for youth, which was organized and led by youth and young adults with disabilities in partnership with YO! Disabled & Proud. California Foundation for Independent Living Centers (CFILC) Executive Director Christina Mills, CFILC Project Yo! Youth Organizer Yolanda Vargas, Office of Clients' Rights Advocacy peer advocate Scott Barron, and California Leadership Education in Neurodevelopmental and Related Disabilities Trainee Lynda Karl organized and facilitated the program, which included:

- Moving from Youth to Adult Healthcare Systems
- Problem Solving and Self Advocacy
- Preparing for Legislative Visits

"This summit has made me a better advocate by giving me hope and encouragement that my situation will and can get better"

LEGISLATIVE DAY

February 27, 2018

More than 70 parents and self advocates convened at the State Capitol for Legislative Day, which began with an overview of key strategies for meeting with legislators from California Children's Hospital Association Director of Government Relations Mira Morton. State Senator Richard Pan, MD shared information about the Senate Select Committee on Children with

"Thank you for the opportunity to be encouraged and empowered to be a voice and be part of a solution"

Special Needs, and he reminded attendees about the importance of their voices. Families and FVCA Executive Council members met with nearly 60

legislators and staff to discuss policy issues, and share personal experiences to illustrate how lawmakers' decisions can affect families of children with special health care needs.



Clockwise from top left: Groups meet with legislators and staff at the State Capitol; Senator Richard Pan, MD kicks off the day; California Children's Hospital Association's Mira Morton shares tips to maximize time with lawmakers

OUTCOMES

Evaluations

- 100% of attendees agreed or strongly agreed that the Summit **increased their knowledge of services and resources for children and youth with special health care needs.**
- 100% of attendees agreed or strongly agreed that they learned **new information about policy issues** that affect families of children and youth with special health care needs.
- 98% of attendees agreed or strongly agreed that the support/information/resources they received from the Summit helped them feel **more confident about getting their child (or the children they serve) the health care and services they need.**



“Great opportunity for us parents to learn tools to advocate for our kids’ needs. I can proudly say I’m transferring these skills to my daughter”

SPONSORS



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SUPPORT FOR FAMILIES
OF CHILDREN WITH DISABILITIES



HEALTH SUMMIT AGENDA

7:30 - 8:30AM	Registration and Continental Breakfast
8:30 - 9:00AM	Welcome and Summit Overview Yvette Baptiste, PhD, Eastern Los Angeles Family Resource Center; Family Voices of California Council member Summit Facilitators: Catherine Blakemore, Disability Rights California Kausha King, Care Parent Network; Parent Advocate
9:00 - 9:15AM	Key Note Address: Assemblymember Blanca Rubio California State Assembly, District 48
9:15 - 10:15AM	Panel: Medicaid/Medi-Cal: Access to Services for Children and Youth with Special Health Care Needs in California <ul style="list-style-type: none">• Moderator: Anne Hall, Parent Advocate• Elissa Gershon, Disability Rights California• Edwin Park, J.D., Georgetown University• Sarah Eberhardt-Rios, California Department of Health Care Services, Integrated Systems of Care Division• Jacob Henley, Maxim Healthcare Services• Jennifer McLelland, Parent Advocate• Larene Pare, Parent Advocate
10:15 - 10:30AM	Table Discussion Groups
10:30- 10:45AM	Break
10:45 - 11:45AM	Panel: The Power of Family Engagement Moderator: Kelly Hardy, Children Now <ul style="list-style-type: none">• Angela Blanchard, Political Solutions• Holly Henry, PhD, Lucile Packard Foundation for Children's Health• Elaine Linn, Family Voices of California Family Engagement Manager• Alison Beier, Parent Advocate• JoAnna Van Brusselen, Support for Families of Children with Disabilities
11:45 - 12:00PM	Table Discussion Groups
12:00 - 12:55PM	Lunch Keynote Address: Assemblymember Dr. Joaquin Arambula California State Assembly, District 31

AGENDA, *continued*

- 12:55 - 1:30PM** **Panel: Legislative Issues and Insights from Staff**
- Moderator:** Ann-Louise Kuhns, California Children's Hospital Association
- Scott Ogus, Senate Committee on Budget and Fiscal Review
 - Joe Parra, Senate Republican Policy Office
 - Paula Villescaz, Assembly Health Committee
- 1:30 - 2:30PM** **Panel: Mental Health**
- Moderator:** Yvette Baptiste, PhD, Eastern Los Angeles Family Resource Center; Family Voices of California Council member
- Senator Jim Beall, California State Senate, District 15
 - Steven Adelsheim, MD, Stanford University Department of Psychiatry
 - Jim Preis, Mental Health Advocacy Services
 - Nicolette Efstathiou, Parent Advocate
 - Magaly Carranco, Self-advocate
- 2:30 - 2:45PM** **Table Discussion Groups**
- 2:45 - 3:00PM** **Break**
- 3:00 - 3:15 PM** **Transition to Breakout Sessions**
- 3:15 - 4:00PM** **Breakout Sessions**
- **Update on CCS and the Whole Child Model Transition in 2018-2019**
 - Laurie Soman, Children's Regional Integrated Service System (CRISS); Lucile Packard Children's Hospital
 - Donnell Kenworthy, Warmline Family Resource Center; Special Grace Ministries; Parent Advocate
 - **Working with Your Regional Center**
 - Katie Hornberger, Disability Rights California
 - **Telehealth - How It Works and What Can It Do for You?**
 - Ielnaz Kashefipour, The Children's Partnership
 - Erin Kelly, Children's Specialty Care Coalition
- 4:00 - 4:30PM** **Open Discussion**
- 4:30 - 5:30PM** **Closing Remarks**
- Legislative Day Information
 - Evaluations

SPEAKERS

- Dr. Steven Adelsheim, Stanford Hospital Edwin Park, Georgetown University
- Assemblymember Joaquin Arambula, MD (31-Fresno)
- Yvette Baptiste, East Los Angeles Family Resource Center
- Senator Jim Beall (15-Santa Clara County)
- Alison Beier, Project Leadership Graduate
- Catherine Blakemore, Disability Rights California
- Angela Blanchard, Political Solutions
- Magaly Carranco, Youth Advocate
- Nicolette Efstathiou, Parent
- Elissa Gershon, Disability Rights CA
- Anne Hall, Project Leadership Graduate
- Kelly Hardy, Children Now
- Jacob Henley, Maxim Healthcare
- Holly Henry, Lucile Packard Foundation for Children's Health
- Katie Hornberger, Disability Rights CA
- Ielnaz Kashefipour, The Children's Partnership
- Erin Kelly, Children's Specialty Care Coalition
- Donnell Kenworth, Parent
- Kausha King, CARE Parent Network
- Ann-Louise Kuhns, California Children's Hospital Association
- Elaine Linn, Family Voices of CA
- Jennifer McLelland, Parent
- Mira Morton, California Children's Hospital Association (Legislative Day)
- Scott Ogus, Senate Committee on Budget and Fiscal Review
- Larene Pare, Lucile Packard Children's Hospital Stanford
- Senator Richard Pan, MD (6-Sacramento) (Legislative Day)
- Joe Parra, Senate Republican Policy Office
- Jim Preis, Mental Health Advocacy Services
- Sarah Eberhardt-Rios, Integrated Systems of Care, DHCS
- Laurie Soman, Children's Regional Integrated Service System, Lucile Packard Children's Hospital
- Assemblymember Blanca Rubio (48-Los Angeles)
- JoAnna Van Brusselen, Support for Families of Children with Disabilities

“As a pediatric provider, it helps knowing about specific ways that I can advocate for my patients, both in my hospital and in government”

ADVISORY COMMITTEE

- Catherine Blakemore, Disability Rights California
- Angela Blanchard, Political Solutions
- Scott Barron, Disability Rights California
- Elena Ford, Parent Advocate
- Allison Gray, Lucile Packard Foundation for Children's Health
- Anne Hall, Parent Advocate
- Kelly Hardy, Children Now
- Lynda Karl, Parent Advocate and UCEDD LEND Trainee
- Ielnaz Kashefipour, The Children's Partnership
- Erin Kelly, Children's Specialty Care Coalition
- Kausha King, CARE Parent Network
- Ann-Louise Kuhns, California Children's Hospital Association
- Katie Layton, Children's Specialty Care Coalition
- Christina Mills, California Foundation for Independent Living Centers
- Kathryn Smith, Children's Hospital Los Angeles
- Laurie Soman, Children's Regional Integrated Service System; Lucile Packard Children's Hospital
- Yolanda Vargas, Yo! Disabled and Proud
- Kelly Young, Warmline Family Resource Center
- Family Voices of California Council Member Agencies

"Nice to verify the needs we are trying to address through our work. It helps us set priorities."