



Family Voices of California

2023 **HEALTH SUMMIT** 





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## THANK YOU TO OUR SPONSORS

















Rady Childrens







# 20th Annual Health Summit **Highlights Report**

March 6th and 7th, 2023

www.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

Tamica Foots-Rachal – Project Director Nick Lutton – Program Manager Elaine Linn – Project Leadership 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 helped me understand that my voice as a parent is extremely powerful."

Project Leadership Graduate



## Family Voices of California 2 0 2 3 HEALTH SUMMIT

#### **PROGRAM OVERVIEW**

General sessions featuring panel discussions and breakout sessions provided a forum for updates and information. Families attending the Summit learned about key issues, and their impact on Children and Youth with Special Health Care Needs (CYSHCN).

## Summit Objectives

This year's Summit featured many healthcare experts involved in policies affecting CYSHCN and their families, and they provided the following information and resources:

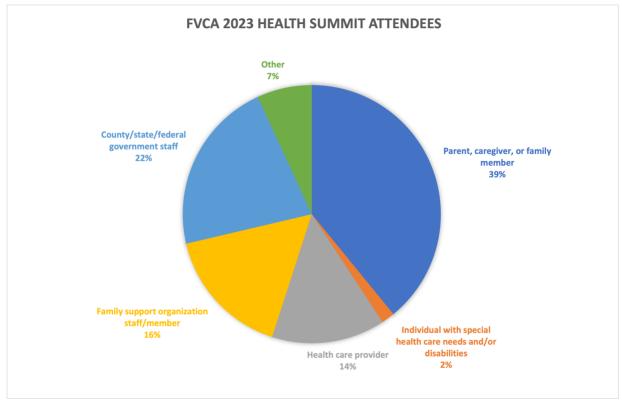
- Information regarding the proposed changes to Medicaid/Medi-Cal programs
- Opportunities to improve mental health treatment and services
- Strategies on meaningful family engagement and partnerships with professionals that serve their family
- Clarity on the unwinding of the public health emergency, and its impact on CYSHCN

## Setting the Tone

Summit moderators Patricia Moore, Director of Help Me Grow Santa Barbara County and Elana Hung, Executive Director, and Co-Founder of Little Lobbyists, took care to lead the charge and set the framework this year by inspiring attendees with key messages to inform, educate, and empower all in attendance.

## Who Attended the 2023 Health Summit?





Graphic A.1 - Attendee breakdown

#### **OUTCOMES**

#### **Evaluations**

To make sure the 2023 Health Summit was able to extend its reach statewide, and remain equitable, this year's advisory committee decided to have a virtual summit to support attendance. Thanks to this foresight, the summit was able to support many families in being informed, self-determined and in their advocacy efforts toward systems change. Here are just a few comments on how this year's summit impacted communication, access, and inclusion:

#### COMMUNICATION

"I feel able to communicate with health care and service professionals"

#### ACCESS IMPROVEMENT

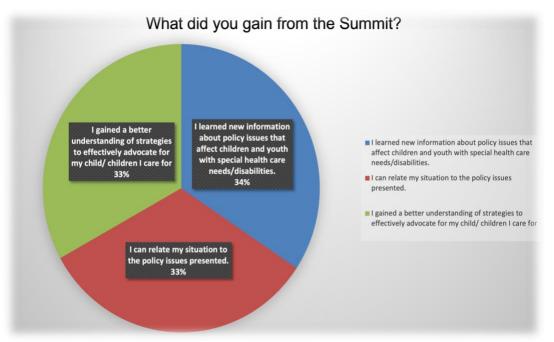
"I feel able to get access to the health services my child/or children I serve needs"

#### **INCLUSION**

"I feel able to participate in policymaking through emails, phone calls, and visits with decision makers.

INCLUSION

The chart below shows that most of the attendees gained a better understanding of strategies, learned new information about policy issues, and could relate their current situation to the issues presented.



Graphic A.2 - Participant Feedback



## FAMILY VOICES OF CALIFORNIA FINAL THOUGHTS...

The 2023 two-day Health Summit event organized by Family Voices Of California was an incredible opportunity for parents and healthcare professionals to come together to share their knowledge and expertise about improving access for children and youth with special healthcare needs.

Over the course of the event, attendees had the opportunity to learn from experts in the field about healthcare, partnering with professionals, mental health and behavior challenge supports, dental care specialist, climate change and pandemic related supports. Many speakers and panelists shared their lived experience about systems navigation and advocacy through interactive participant engagement using breakout sessions, chat, and discussions which provided a chance for attendees to delve deeper into specific topics and exchange ideas and advocacy strategies with one another. This opportunity for peer learning from one another's experiences, allowed all participants to explore new approaches to supporting children and youth with special healthcare needs.

Throughout the event, it was clear that the parents and professionals who attended were genuinely committed to improving access for children and youth with special healthcare needs in all areas of life. Their dedication inspires others and demonstrates the power of collective action in creating positive change in healthcare policy and practice.



FAMILY VOICES OF CALIFORNIA THANKS ALL OF OUR FAMILIES FOR PARTICIPATING, SPEAKERS, MODERATORS, PANELISTS AND SUPPORT STAFF. WE ALSO THANK THE FOLLOWING:

## **Advisory Committee**

- Family Voices of California Council Member Agencies
- Allison Gray, Lucile Packard Foundation for Children's Health
- Amy Blumberg, CCHA
- Andy Imparato, Disability Rights CA
- Angela Blanchard, Children's Specialty Care Coalition
- Anne Hall, Parent, PL Graduate
- Brianna Pittman-Spencer, CA Dental Association
- Carol Cohen, FRN (FVCA Executive Council member)
- Erin Kelly, Children's Specialty Care Coalition
- Kathryn Smith, Children's Hospital Los Angeles
- Katie Layton, Children's Specialty Care Coalition
- Kausha King, Parent, PL Graduate
- Kelly Hardy, Children Now
- Laurie Soman, Children's Regional Integrated Service Systems (CRISS)
- Linda Landry, Family Voices of California
- Martha Ornelas, ELAFRC (FVCA Executive Council member)
- Patty Moore, Alpha Family Resource Center (FVCA Executive Council member)
- Sarah Leff, CA maternal child adolescent health/ Title V
- Teresa Anderson, The Arc of CA
- Wendy Neikirk-Rhodes, Support for Families of Children with Disabilities (FVCA Executive Council member)
- Yvette Baptiste, East Los Angeles Family Resource Center (FVCA Executive Council member)
- Michelle Sepulveda, East Los Angeles Family Resource Center (FVCA Executive Council member)

## **Sponsors**

- California Dental Association
- Lucile Packard Foundation
- CalOptima Health
- Stanford Medicine Childrens Health
- Pediatric Day Health Care Coalition
- Childrens Specialty Coalition
- Central California Alliance for Health
- California Childrens Hospital Association
- Rady Childrens Hospital, San Diego
- CenCal Health
- Valley Childrens Healthcare
- Partnership of California Health Plan



A SPECIAL THANKS TO PIP MARKS,
PROJECT DIRECTOR FOR FAMILY
VOICES OF CALIFORNIA UNTIL MARCH
OF 2023 AND 2023 HEALTH SUMMIT
ORGANIZER, FOR ALL OF PIPS HARD
WORK, COMMITMENT, DEDICATION AND
ADVOCACY TO SUPPORT FAMILIES OF
CHILDREN WITH SPECIAL HEALTH CARE
NEEDS THROUGHOUT CALIFORNIA.

#### 2023 HEALTH SUMMIT RELATED MATERIALS

- Agenda
- Breakout Session Overviews
- PowerPoints
- Speakers Bios

#### 2023 HEALTH SUMMIT VIDEOS:

- Keynote: Elena Hung, Little LobbyistsCal-AIM and Enhanced Care Management
   — what does this mean for Children and Youth with Special Health Care Needs/Disabilities

   — https://www.youtube.com/watch?v=5N7jjcSqIAU
- Telehealth and Access to Care for CYSHCN https://www.youtube.com/watch?v=tgFJNxfdCxk
- Partnering with Your Regional Center to Meet Your Child's Needs <a href="https://www.youtube.com/watch?v=4xqz2YDVf6Q">https://www.youtube.com/watch?v=4xqz2YDVf6Q</a>
- CA Children's Services (classic) and the Whole Child Model https://www.youtube.com/watch?v=jX0c4AfU6eQ
- A Rare Disease Advisory Council (RDAC) Opportunities and Challenges for the Community https://www.youtube.com/watch?v=NJkf72kIZUI
- Keynote: The Impact of Public Health Emergency Unwinding for CYSHCN/Disabilities https://www.youtube.com/watch?v=TUJ6Y\_ILKPg
- Keynote: Senator Anthony Portantino/ Behavioral Health and Children and Youth with Special Health Care Needs: Challenges and Opportunities https://www.voutube.com/watch?v=TMx29Glm- c
- **Dental Care for CYSHCN**https://www.youtube.com/watch?v=uyhlhOB5Nvo
- Climate Change effect for CYSHCN https://www.youtube.com/watch?v=hPoBxkDsnDk
- Impact of Pandemic on Child Development Moving Forward https://www.youtube.com/watch?v=6EepC63SQpY
- Young adults panel Lived Experience "Developing Positive Disability Identity https://www.youtube.com/watch?v=KbyNpgb8olU

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