

FAMILY VOICES of California

2013 HEALTH SUMMIT & LEGISLATIVE DAY
FEBRUARY 25-26

HIGHLIGHTS



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

2013 HEALTH SUMMIT AND LEGISLATIVE DAY

Family Voices of California (FVCA) is a statewide collaborative of 8 locally-based parent-run centers working to ensure quality health care for children and youth with special health care needs. On February 25 2013, FVCA held its 11th annual statewide Health Summit in Sacramento, bringing together families, advocates, state agency representatives, health policy advocates, legislative representatives, providers and insurers. Long before the event the FVCA 2013 Summit Advisory Committee, made up of families and professionals (see page 8 for the list) worked together to create the day.

The vision for the 2013 Summit was defined as a world where our children's health care is self determined, family centered, and quality health care is the norm. The Summit's objectives included enabling families and providers to learn how budgets and legislation impact access to services, and identifying upcoming ballot initiatives and legislative items to watch. Throughout the Summit, families would have their voices heard regarding the impact of the budget on their children's health care and related services.

The 2013 Health Summit was held at the Sacramento Convention Center. Through the support of generous sponsors (see page 7), Family Voices of California provided translated materials, a Spanish interpreter, breakfast and lunch as well as caregiving for 14 children of attending families.

This year's Health Summit proved to be a great success with a total of 103 participants, including 38 parents or adult family members, and 6 youth. They represented diverse areas of the state from Humboldt County in the north to San Diego in the south.

This year's Summit featured many experts in the field. The Summit moderator, **Catherine Blakemore, Executive Director Disability Rights California**

set the tone and enhanced the day with thoughtful insights. **Jane Ogle, Deputy Director, Health Care Delivery Systems, California Department of Health Care Services**, provided an overview of California and was very conscientious about answering all the questions that came her way. **Edwin Park, Senior Fellow, Center for Budget Priorities**, gave an overview of the federal budget and Scott

Graves focused on the California budget. **Assembly Member Holly Mitchell** gave an insiders look from a legislator's perspective. **Lisa Chan-Sawin of Harbage Consulting** provided a clear and concise overview of the Affordable Care Act and Exchange, no easy task. After lunch **Kathryn Smith, Associate Director for Administration; USC University Center for Excellence in Develop-**

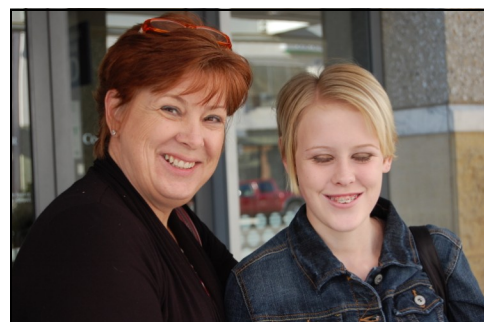
mental Disabilities Children's Hospital Los Angeles, facilitated a diverse panel of speakers who addressed access to care coverage. They focused on things to celebrate, things to worry about, what to strive for and opportunities for participation.

Every year at the FVCA Summit we take time to have breakout sessions for group discussion. FVCA Council Member Agency representatives guide the conversation with questions: "What did you hear that surprised you?" "What services do you rely on and why are they important to your child?" "What are positive impacts that you heard?" "What are your priority issues and do you have personal stories that demonstrate those concerns?" The purpose of breakout is to help families digest what they



"I want to be a mom — not an insurance cost analyst. However if we are going to be making those decisions then we should be at the table as [policymakers] are making decisions."

-Parent at FVCA 2013 Health Summit



heard, to reflect on what they have heard, and to write down points they want to discuss with their legislators the following day.

Last, but certainly not least, was a presentation by **Dr. David Alexander President and CEO of the Lucile Packard Foundation for Children’s Health** titled *What’s Next: A Funders Perspective*.

Before leaving the summit, participants responded to evaluations and wrote down actions they were going to take once they returned home. They put their lists in self-addressed envelopes, which they will receive within 2 months to remind them of their commitment.

After the Summit, family members and FVCA Council Member Agency staff networked at a family dinner.

On February 26, 43 participants, including parents, their children and youth got up early to meet at the State Capitol for Legislation Day. The day began with presentations from **Catherine Blakemore and Evelyn Abouhassan from Disability Rights California**, who presented key strategies for meeting with legislators and encouraged participants by reminding them that their voices are important and they deserve to be heard. The participants then fanned out to meet with 40 legislators or their staffs to discuss policy issues and exchanged information to continue the dialogue beyond the Summit.

In an evaluation of the Summit, participants overwhelmingly responded that the conference enabled them to take action and address policy issues affecting children with special health care needs (please see page 6).

“A great step towards becoming a better advocate for my own children as well as other families!”
-Parent at FVCA 2013 Health Summit





“Thank you to all who put this info together for families who have kids with disabilities and special needs. I hope more parents realize this exists, so that there will be more voices at the governmental level.”

-Parent at FVCA 2013 Health Summit



DISTINGUISHED SPEAKERS

Family Voices of California was honored to provide a platform for the following presenters who made the Health Summit a success.

February 25, 2013 Presentations

Juno Duenas, Executive Director
Support for Families and Council Member, Family Voices of California

Catherine Blakemore Executive Director,
Disability Rights California

Jane Ogle, Deputy Director, Health Care
Delivery Systems, DHCS

Edwin Park, Senior Fellow, Center for
Budget Priorities

Scott Graves, Senior Policy Analyst, California
Budget Project

Assembly Member Holly Mitchell

Lisa Chan-Sawin, Harbage Consulting

Kathryn Smith, Associate Director for
Administration; USC University Center for
Excellence in Developmental Disabilities
Children's Hospital Los Angeles

Mike Odeh, Associate, Health Policy,
Children Now

Mark Edelstein, Medical Director, EMQ
FamiliesFirst

Ana Clark, Manager, State Health Programs,
Health Net, Inc;

Feda Almaliti, Parent, Autism Health
Insurance Project

David Alexander, President and CEO,
Lucile Packard Foundation for Children's
Health

February 26, 2013 Legislative Day

Catherine Blakemore Executive Director,
Disability Rights California

Evelyn Abouhassan Disability Rights
California

11th Annual Health Summit

Learn Together. Support our children's health care needs together.

March 25th, 2013

Sacramento Convention Center
1400 J Street, Sacramento

AGENDA



8:30 - 9:00 AM **Registration**

9:00 - 9:15 AM **Welcome and Overview of Summit**

Juno Duenas Family Voices of California Council Member
Moderator: **Catherine Blakemore** Executive Director, Disability Rights California

9:15 - 10:15 AM **Overview of California**

Jane Ogle, Deputy Director, Health Care Delivery Systems, DHCS

10:15-11:00 AM

Federal and State Overview

The Federal Budget what's going on in the nation?

Edwin Park, Vice President for Health Policy, Center on Budget and Policy Priorities

The California Budget

Scott Graves, Senior Policy Analyst, California Budget Project

11:00 - 11:15 AM

Break

11:15 -11:30 AM

A Legislator's Perspective

Assembly Member Holly Mitchell

11:30-12:15 PM

Affordable Care Act and Exchange – What are the Specifics?

Lisa Chan-Sawin, Harbage Consulting

12:15 -12:45 PM

Lunch

12:45-2:15 PM **Access to Care Coverage: Options for CSHCNs**

Facilitator: **Kathryn Smith**, Associate Director for Administration USC University Center for Excellence in Developmental Disabilities Children's Hospital Los Angeles

Panel: **Mike Odeh**, Senior Health Policy Associate, Children Now; **Mark Edelstein**, Medical Director, EMQ FamiliesFirst; **Ana Clark**, Manager, State Health Programs, Health Net, Inc; **Feda Almaliti**, Parent, Autism Health Insurance Project

2:15-2:30 PM

Break

2:30-3:30 PM

Group Discussion

3:30-4:00 PM

Report Back

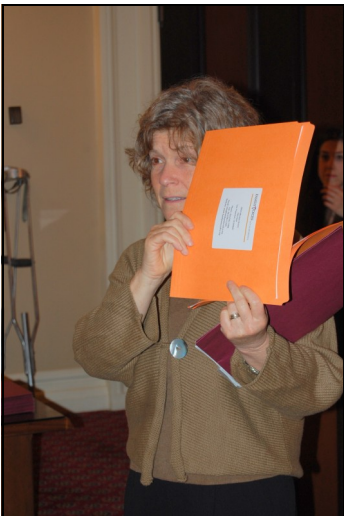
4:00 -4:25 PM

What's next?

David Alexander, President and CEO, Lucille Packard Foundation for Children's Health

4:25-5:00 PM

Closing Remarks & Legislative Day Information Evaluation

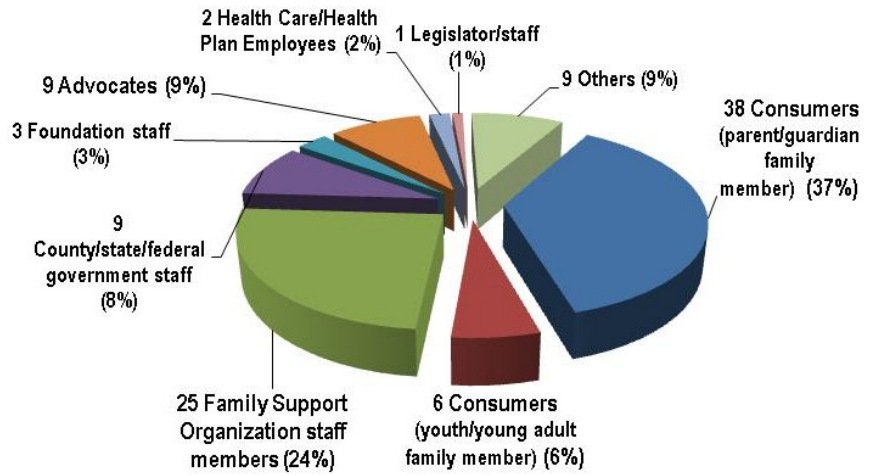


FVCA HEALTH SUMMIT AND LEGISLATIVE DAY

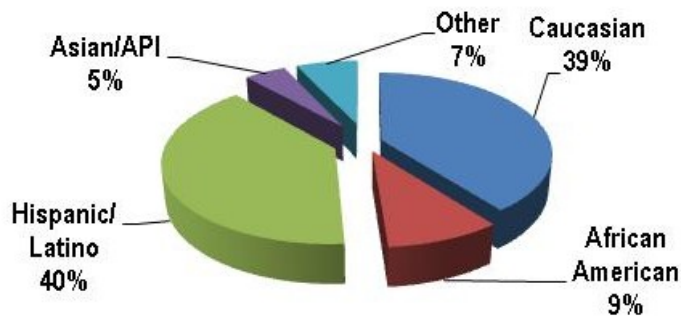
SUMMARY AND EVALUATION

Attendance

The Summit had **103 participants** this year, with the majority being parents, advocates, or staff of parent centers.



Diversity



“I was very inspired to see so many people from different backgrounds and life experiences coming together to take action.”

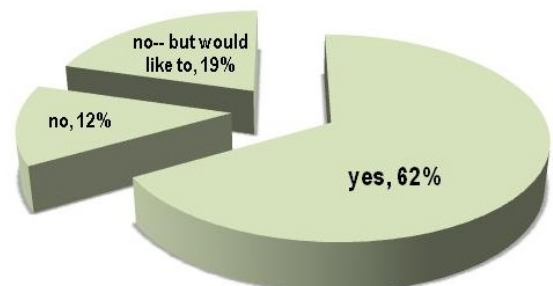
-Participant at FVCA 2013 Health Summit

Evaluation

In their evaluation surveys, participants identified the ways the Summit impacted them.

- ▶ 97% agreed or strongly agreed that the Summit **increased their knowledge of services and resources for children and youth with special health care needs.**
- ▶ 98% agreed or strongly agreed that they learned **new information about policy issues** that affect families of children and youth with special health care needs.
- ▶ 91% 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.**

Do you currently participate on committees, task forces, advisory boards, and at other levels of program and/or policy?



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Lucile Packard
Children's Hospital
at Stanford

THANK YOU

Family Voices of California 2013 Summit Advisory Committee

Charity Bracy CA Children's Hospital Association
Chris Hoene CA Budget Project
Ed Schor Lucile Packard Foundation for Children's Health
Elisabeth Hoy, Patient and Family Centered Care Partners
Janice Milligan, HealthNet
Janice Connallon, Lucile Packard Foundation for Children's Health
Kathryn Smith, University of Southern CA; University Center for Excellence in Developmental
Disabilities at Children's Hospital Los Angeles
Laurie Soman, CRISS Project, Lucile Packard Children's Hospital
Mike Odeh, Children Now
Mark Polit, State Council on Developmental Disabilities
Tony Anderson, The Arc of CA

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