

FAMILY VOICES of California

2014 HEALTH
SUMMIT &
LEGISLATIVE
DAY
February 24-25



The voice of families
The vision of quality
health care

The future for
children and youth
with special health
care needs

2014 HEALTH SUMMIT AND LEGISLATIVE DAY: HIGHLIGHTS

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

On February 24, 2014, FVCA held its 12th 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 2014 Summit Advisory Committee, made up of families and professionals, (see page 7 for the list) worked together to create the day.

"I feel inspired and empowered to get more involved in children's health policy and to improve the quality of care for my child."

-parent at Health Summit

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

have a better, clearer understanding of how the Affordable Care Act (ACA), Medi-Cal and Covered California affect children and youth with special

health care needs (CYSHCN) and their access to needed services. All participants learned about the key components, benefits and concerns for the California Children's Services (CCS) program, how to access behavioral services through schools, Medi-Cal and private insurance as well as the oversight and monitoring of Medi-Cal Managed Care after the transition of Healthy Families to Medi-Cal. Family members who attended the Summit learned how to present issues regarding their CYSHCN to their legislators in preparation for the following day at the Capitol.

This year's Health Summit proved to be a great success with a total of 133 participants, including 64 parents or adult family members, and 11

youth. They represented diverse areas of the state from Humboldt County in the north to San Diego in the south. There were more than 58 professionals from government agency staff, health care providers and other health-related organizations attending. Thanks to the support of generous sponsors (see p. 11), Family Voices of California provided breakfast and lunch as well as caregiving for 10 children of attending families.

Speakers Set the Tone

This year's Summit featured many experts in the field of healthcare pertaining to children and youth with special healthcare needs. The Summit moderator, **Catherine Blakemore, Executive Director Disability Rights California**, set the tone and enhanced the day with thoughtful insights. **Anne Louise Kuhns, President & CEO at California Children's Hospital Association**, began the day with a plenary address. Ann gave an overview of the current state of healthcare for people in California who live with disabilities.

Laurie Soman, CRISS Executive Director and Senior Policy Analyst at Lucile Packard Children's Hospital, provided an overview of California Children's Services (CCS) and facili-



Catherine Blakemore, Executive Director, Disability Rights California

The vision for the 2014 Summit was defined as a world

tated a panel of experts on the future of CCS. The panel consisted of **Dr. Lisa Chamberlain** from Lucile Packard Children's



State Senator Holly Mitchell

Hospital; Kathryn Smith, Associate Director for Administration USC and University Center for Excellence in Developmental Disabilities Children's Hospital Los Angeles; Katie Schlageter from Alameda CCS and Libby Hoy, founder and CEO of Patient and Family Centered Care Partners. The panel

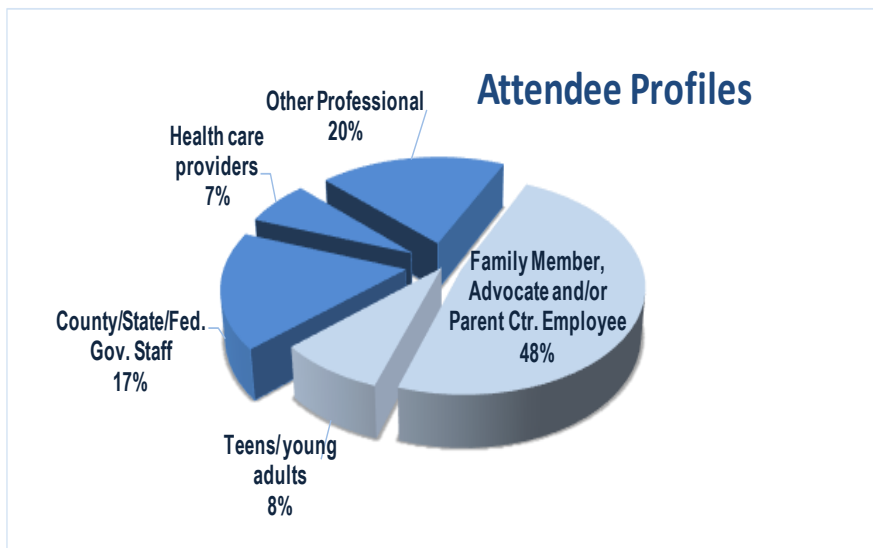
"I was able to learn updated information, concerns and education from experts. It was great!" -parent

tal Disabilities Children's Hospital Los Angeles; Katie Schlageter from Alameda CCS and Libby Hoy, founder and CEO of Patient and Family Centered Care Partners. The panel

continued on page 4

Participants

133 parents, advocates, youth, or staff of parent resource centers attended the Summit. In addition, 10 children used the free childcare.



Evaluation

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

► 98% 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.

► 88% 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.**

*59 participants completed surveys.

"The Summit helped me network with other parents and providers that are in similar situations who are knowledgeable regarding special health care needs. It helped me feel involved and proactive." -parent

addressed specific issues and concerns for the CCS program.

Senator Holly Mitchell received a full-house standing ovation for her inspirational keynote address from a legislator's perspective.

transition for children and youth with special health care needs. The panel of speakers included **Marilyn Holle, Associate Attorney at Disability Rights California; Mike Odeh, Health Policy Associate at Children Now** and **Vanessa**

might benefit their child's health care; What they heard that might have a negative impact on their child's health care and what they heard that they wanted to tell their legislator the next day to help them understand health care for their child and other children/youth with special health care needs. At the end of the day, all attendees re-grouped to discuss benefits and concerns and to prioritize three key points on what they could do with the information they just learned and what they could do NOW with all they learned.



Mental Health Panel

Panels Spark Discussion

After lunch **Kathryn Smith**, facilitated a diverse panel of speakers who addressed accessing behavioral services through schools, Medi-Cal and private insurance. The Mental Health panel consisted of **Maggie Roberts, Associate Attorney from Disability Rights California (DRC); Jane Ogle, Deputy Director of Health Care Delivery Systems (DHCS), Dr. Terry Rooney, Mental Health Director for Colusa County** and **Susan Montana from Health Net in CA.**

The third panel discussion, facilitated by **Laurie Soman**, addressed the oversight and monitoring of Medi-Cal Managed Care after the Healthy Families

Cajina at Western Center on Poverty and Law.

During the day, there were two opportunities for the Summit attendees to break out into small discussion groups. FVCA Summit Advisory Council members facilitated the conversations. The purpose of the breakouts is to help families digest and reflect on what they have heard, and to identify points they want to discuss with their legislators the following day. Following the CCS panel presentations, the groups discussed: What they heard that

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 will be mailed to them within two months to remind them of their commitment.

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



Ginger MacGowan, Rowell Family Empowerment

Legislative Day

On February 25, 49 participants, including parents, their children and youth got up early to meet at the State Capitol for Legislative Day. The day began with presentations from **Evelyn Abouhassan from Disability Rights California** and **Assemblymember Tom Ammiano, 17th District San Francisco**, 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

As a provider .. [I have] increased empathy for parents. Great to be with providers/families/advocates - a wide variety of people interested in a common goal!

-professional at Health Summit

participants then fanned out to meet with over 25 legislators or their staffers 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 3). ■



Rowell Family Empowerment participants meet with Assemblymember Logue's staff



Assemblymember Tom Ammiano with Legislative Day participants



State Senator Jean Fuller with Vicki Slater and Timaree Torres

12TH ANNUAL HEALTH SUMMIT 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 and Executive Director of Support for Families of Children with Disabilities Summit Moderator: Catherine Blakemore , Executive Director, Disability Rights California
9:15 - 9:45AM	PLENARY: Current State of Healthcare for People with Disabilities in CA Ann-Louise Kuhns , President & CEO, California Children's Hospital Association
9:45 - 11:00 AM	The Future of California Children's Services: specific issues and concerns for the program Facilitator: Laurie Soman , CRISS and Lucile Packard Children's Hospital Panel of Speakers: Dr. Lisa Chamberlain , Lucile Packard Children's Hospital; Kathryn Navarette Smith , Associate Director for Administration, USC UCEDD; Katie Schlageter , Alameda CCS; Elizabeth (Libby) Hoy , Founder and CEO, Patient & Family Centered Care (PFCC) Partners
11:00 - 11:15 AM	Break
11:15 - 11:45 AM	Group Discussion
11:45 - 12:30 PM	Lunch
12:30 - 1:00 PM	A Legislator's Perspective Senator Holly Mitchell
1:00 - 2:00 PM	Mental Health: Accessing behavioral services through schools, Medi-Cal and private insurance Facilitator: Kathryn Smith , Associate Director for Administration, USC UCEDD Panel of Speakers: Maggie Roberts , Associate Attorney, Disability Rights California; Jane Ogle , Deputy Director Health Care Delivery Systems, DHCS; Terry Rooney PhD , Mental Health Director, Colusa County; Susan Montana from Health Net
2:00 - 2:15 PM	Break
2:15 - 3:15 PM	Oversight, monitoring of Medi-Cal managed care, post healthy families transition for CSHCN Facilitator: Laurie Soman , CRISS and Lucile Packard Children's Hospital Panel of Speakers: Marilyn Holle , Associate Attorney, Disability Rights California; Mike Odeh , Health Policy Associate, Children Now; Vanessa Cajina , Western Center on Poverty and Law
3:15 - 4:00 PM	Group Discussion
4:00 - 4:30 PM	Report Back
4:30 - 5:00 PM	Closing Remarks & Legislative Day Information Evaluation Catherine Blakemore , Executive Director, Disability Rights California

DISTINGUISHED SPEAKERS

Family Voices of California was honored to hear from the following presenters who made the Health Summit a success.

February 24: Health Summit

Catherine Blakemore, Executive Director, Disability Rights California

Vanessa Cajina, Western Center on Law and Poverty

Lisa Chamberlain, MD, MPH
Stanford School of Medicine and
Packard Children's Hospital

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

Marilyn Holle, Senior Attorney,
Disability Rights California

Elizabeth (Libby) Hoy, Founder
and CEO, Patient & Family
Centered Care (PFCC) Partners

Ann-Louise Kuhns, President &
CEO, California Children's Hospital
Association

Senator Holly J. Mitchell, 26th
District, Los Angeles, CA

Susan Montana, MS, MFT,
Managed Health Net (MHN)

Mike Odeh, Senior Health
Policy Associate, Children Now

Jane Ogle, Deputy Director
Health Care Delivery Systems,
DHCS

Maggie Roberts, Associate
Managing Attorney with
Disability Rights California

Terence M. Rooney, Ph.D.,
Mental Health Director, Colusa
County Behavioral Health

Katie Schlageter, Alameda
County Public Health Dept. ,
Family Health Services Division,
Oakland

Kathryn Navarette Smith,
Associate Director for
Administration, USC UCEDD

Laurie A. Soman, Senior Policy
Analyst, Lucile Packard Children's
Hospital and CRISS Executive
Director



Laurie Soman, CRISS & Lucile Packard Children's Hospital

February 25: Legislative Day

Evelyn Abouhassan, Disability
Rights California

**Assemblymember Tom
Ammiano**, 17th District, San
Francisco, CA

THANK YOU!

Family Voices of California 2014 Summit Advisory Committee

Catherine Blakemore, Disability Rights California

Janis Connallon, Lucile Packard Foundation for Children's Health

Elizabeth Hoy, Patient and Family Centered Care Partners

Mike Odeh, Children Now

Mark Polit, State Council on Developmental Disabilities

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

Key Issues for CA Families of Children with Special Health Care Needs -

FVCA identified the following key issues for California's children with special health care needs and their families based on the federal **Maternal Child Health Bureau** Critical Systems Outcomes set out in the **Healthy People 2020 National Health Objectives**:

♦ Family/Professional Partnership at All Levels of Decision Making

- ✓ Ensure that families participate at all levels, and are included in planning, monitoring and evaluating systems changes. Families must be included in state and local health care-related committees and task forces. It is critical that families who are impacted by changes and new programs have input on what might work best and how changes might impact them and their children. FVCA family members are eager to participate. Families' voices need to be heard.

♦ Access to Coordinated Comprehensive Care within a Medical Home

Strengthen Medi-Cal Program's Capacity to Serve CSHCN

- ✓ Conduct an evaluation of the transition of Healthy Families to Medi-Cal in 2013 and its results on access to care, including access to care specifically for CSHCN.
- ✓ Address the adequacy of Medi-Cal provider networks for children, including pediatricians and pediatric sub-specialists, and release the evaluation results to the public.
- ✓ Restore provider reimbursement levels to ensure that Medi-Cal has adequate pediatric primary and subspecialty providers, DME and medical supply vendors, in-home nursing, pharmacists, audiologists, and other critical service providers.
- ✓ Evaluate the impact of Medi-Cal service delivery changes on CSHCN, including mandatory enrollment of people with disabilities into Medi-Cal managed care, and release the results to the public.
- ✓ Evaluate the impact of the expansion of managed care into rural counties and ensure that access of CSHCN to their historic providers and services is preserved.

Improve Access to Mental Health Services

- ✓ Ensure there are enough mental health specialists to address the needs of our children and youth who need their expertise.
- ✓ Ensure that the role parents play in their children's lives is preserved, including the right to make informed and meaningful decisions regarding their child's education and their child's benefits. Families are now asked to consent to allow their school district to access their child's public benefits or insurance; this can leave them without the necessary service coverage for services they need to have at home.



♦ Access to Adequate Private and/or Public Insurance to Pay For Needed Services

Address Needs of CSHCN in Implementation of “Covered California”

- ✓ Ensure that the essential health benefit package, as defined by the state’s benchmark plan, meets the needs of all children, including CSHCN, by requiring coverage of and timely access to pediatric subspecialty care, pediatric-appropriate mental health services, pediatric durable medical equipment (DME) and medical supplies, pediatric-appropriate medications, and pediatric habilitation services.
- ✓ Evaluate access to these services under Covered California plans for enrolled children, particularly CSHCN, and make changes to the benchmark plan as necessary to protect access to the essential pediatric benefits.

Preserve California Children’s Services (CCS) Program’s Services and Standards

- ✓ Ensure that the state maintains and enforces state CCS standards for pediatric subspecialty providers, including hospitals, Special Care Centers, and physicians.
- ✓ Ensure that the essential components of the CCS program, including state quality standards, timely access to appropriate pediatric sub-specialty care, medical case management and care coordination, are maintained for CSHCN, as the state considers changes to the health care delivery system serving children eligible for the program.
- ✓ Maintain the CCS carve-out from Medi-Cal managed care until alternative proposals have been evaluated, evaluation results have been analyzed and released publicly, and preservation of essential CCS components is ensured.
- ✓ Promote collaboration of state and county CCS to identify and implement program changes to make CCS more efficient, effective, and family-friendly.



♦ Early and Continuous Screening for Special Health Needs

- ✓ CA must create a system for screening, including supporting universal screening of young children for developmental and behavioral concerns and availability of early intervention and treatment services.



♦ Organization of Community Services for Easy Use

- ✓ Ensure that children, including CSHCN, can obtain the high-quality child care services they need by restoring funding for lost child care slots.

♦ Youth Transition to Adult Health Care, Work, and Independence

- ✓ CA must create a system for transition, including ensuring successful transition to an adequate supply of adult-oriented health care providers.



"The amount of agencies, professionals and elected officials that are involved... helped me realize that there is a collaboration to make changes. The summit also let me know that my story and voice can and needs to be heard." -parent

"I feel annoyed that families have to go through so much to access quality care for their children. I am passionate in helping CSHCN and even more so after this summit!"

-parent

"I have a greater, more in-depth understanding of systems available for CSHCN I feel like I have knowledge to share with others. I have been empowered to use this information at work."

-professional



OUR GENEROUS 2014 SPONSORS:



CALIFORNIA
HEALTHCARE
FOUNDATION



Health Net®



Tri-Counties
Regional Center



Legislative Day participants from Support for Families

Who Are We?

Family Voices of California (FVCA) is a statewide collaborative of locally-based parent run centers working to ensure quality health care for children and youth with special health care needs (C/YSHCN). 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. We are the State Affiliate of Family Voices National and California's federally-funded "Family to Family Health Information Center."

FVCA supports families of children with disabilities across California

- ▶ **Support, Navigation and Community-Based Services.** FVCA member agencies help families as they explore the barriers to health care through parent education, referrals, counseling, resource libraries, and other services. Parent-run organizations have knowledge and experience with the racial, ethnic, cultural, and linguistic needs of families in their areas and build trusting relationships with families who can be uncomfortable with systems.
- ▶ **Statewide Learning Opportunities.** We offer monthly Brown Bag Lunch Webinars on health and policy issues for professionals and families.

FVCA helps families improve health care for children in California



- ▶ **Annual Statewide Health Summits.** To educate families about the legislative and health care systems and give them a chance to improve health care for children with special health care needs by building a relationship with their legislators.
- ▶ **Putting a Face on the Numbers.** We infuse stories from real families into discussions about policies. As co-authors on the 2009 report "California's Service System for Children and Youth with Special Health Care Needs: Analysis and Recommendations for a Service System that Works for Children and Families," we collected

and provided stories to highlight the health care experiences of families with children with disabilities.

- ▶ **Participate in Policy Development.** We keep up-to-date on policy development that impacts children and youth with special health care needs. We work closely with the Department of Health Care Services on the 1115 waiver, with the CCS Department, on the Title V Needs Assessment and other key partners.
- ▶ **National Impact.** We reach beyond California by collaborating with Family Voices State Affiliates and National partners.

FVCA COUNCIL MEMBERS

San Francisco County

Coordinating Office: Support for Families
1663 Mission Street, Suite 700 San Francisco, CA 94103
Phone: 415.282.7494 Fax: 415.282.1226
Email: pmarks@familyvoicesofca.org
Contact: **Pip Marks**

Butte, Glenn, Shasta, Siskiyou, Tehama & Trinity Counties

Rowell Family Empowerment of Northern California
962 Maraglia Redding, CA 96002
Toll Free: 877-227-3471
Local: 530-226-5129 Fax: 530-226-5141
Email: wendy.longwell@rfenc.org
Contact: **Wendy Longwell**

Los Angeles County

Westside Family Resource and Empowerment Center
5901 Green Valley Circle #320 Culver City, CA 90230-6953
Phone: 310-258-4063; 323-717-7411 Fax: 310 338-9664
Website: www.westsiderc.org
email: family@westsiderc.org
Contact: **Linda Joy Landry**

Eastern Los Angeles Family Resource Center
1000 South Fremont Avenue Suite 6050, Unit 35
Alhambra, CA 91803
Phone: 626-300-9171 Fax: 626-300-9164
Website: www.easternlafrc.org
Email: coordinator@elafrc.net
Contact: **Yvette Baptiste**

Alameda County

Family Resource Network
5232 Claremont Avenue Oakland, CA 94618
510.547.7322 Fax 510.658.8354
Email: frn@frnoakland.org
Contact: **Eileen Crumm**

Santa Barbara County

Alpha Resource Center, Family First Program
4501 Cathedral Oaks Road Santa Barbara, CA 93110
Phone: 805.683.2145 Fax: 805.967.3647
Email: info@alpharesourcecenter.org
Contact: **Patty Moore**

San Diego, & Imperial Counties

Exceptional Family Resource Center
9245 Sky Park Court, Suite #130 San Diego, CA 92123
Phone: 619.594-7416 Fax 858.268.4275
Toll Free: 800-281-8252
Email: efrc@projects.sdsu.edu
Contact: **Sherry Torok**

Fresno, Kings County

EPU Children's Center
4440 North First Street Fresno, CA 93726
559.229.2000 x193 Fax: 559.229.2956
Website: www.epuchildren.org
Email: abreedlove@epuchildren.org
Contact: **Amy Breedlove**