

FAMILY  VOICES  
of California

# 14th Annual Health Summit And Legislative Day



# HEALTH SUMMIT HIGHLIGHTS

Family Voices of California (FVCA) is a statewide collaborative of 7 locally-based parent-run centers working to ensure quality health care for children and youth with special health care needs (CYSHCN). On March 14, 2016 FVCA held its 14th annual statewide Health Summit in Sacramento, bringing together families, advocates, state agency representatives, health policy advocates, legislative representatives, and health care providers. The vision for the 2016 Summit was defined as a world where our children's health care is self determined, family centered, and quality health care is the norm.

Long before the event, the FVCA 2016 Summit Advisory Committee, made up of families and professionals, (see p. 16) worked together to create the day. The Summit's objectives included enabling families, health care providers, advocates for CYSHCN to learn about proposed changes to the California Children's Services (CCS) program after the carve out ends in January 2017; having a better, clearer un-

derstanding of CA Medi-Cal Managed Care program for CYSHCN as well as learning about Mental Health Services for children and youth in CA. 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 138 participants, including 71 family members. They represented diverse areas of the state from Humboldt County in the north to San Diego in the south. There were 67 professionals from government agency staff, health care providers and other health-related organizations attending.

Thanks to the support of generous sponsors (see p. 15), Family Voices of California provided breakfast and lunch as well as free caregiving for 8 children of attending families.

## Speakers Set the Tone

This year's Summit featured many experts in the field of healthcare pertaining to CYSHN. The Summit moderators, **Catherine Blakemore**, Executive Direc-

tor Disability Rights California; **Michele Byrnes**, a parent and FVCA Project Leadership graduate; and **Ann Louise Kuhns**, CEO of CA Children's Hospital Association set the tone and enhanced the day with thoughtful insights. **State Senator Richard Pan** began the day with a plenary address. As Chair of the Senate Select Health Committee, Senator Pan has set a high priority for addressing the health care needs of CYSHCN.

**Catherine Blakemore** facilitated the first panel of expert speakers who addressed the Department of Health Care Services specific issues and challenges as well as successes in the Medi-Cal managed Care program for CYSHCN. The panel consisted of **Dr. Greg Buchert**, California Health and Wellness; **Linda Nguy**, Western Center on Law and Poverty; **Tony Maynard**, Hemophilia Council; and **Kelly Hardy**, Children Now

For the second panel of speakers in the morning, **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 facilitated a panel of experts on the future of CCS and the proposed changes to the CCS program. The speakers included **Jennifer Kent**, Director of the Department of Health Care Services; **Yvette Baptiste**, Family Voices of California Council Member and Executive Director of Eastern Los Angeles Family Resource Center; **Kausha**

**The vision for the 2016 Summit: a world where our children's health care is self determined, family centered, and quality health care is the norm.**

**King**, a parent and FVCA Project Leadership Graduate; **Ann Louise Kuhns**, California Children's Hospital Association; and **Kelly Hardy**, Children Now.

After lunch **Christina Mills**, California Foundation for Independent Living Centers moderated the panel on Mental Health. **Diane E. Van Marren**, Public Policy Consultant and National Alliance for Mental Illness (NAMI) of California Board Member gave an overview of current Mental Health Services in CA for children and youth in CA. The Panel of expert speakers included: **Maggie Roberts**, Disability Rights California; **Dr. Peter Currie**, Inland Empire Health Plan; **Jenny Kattlove**, The Children's Partnership and **Barbara Sheehy**, Alameda CCS Mental Health Initiative.

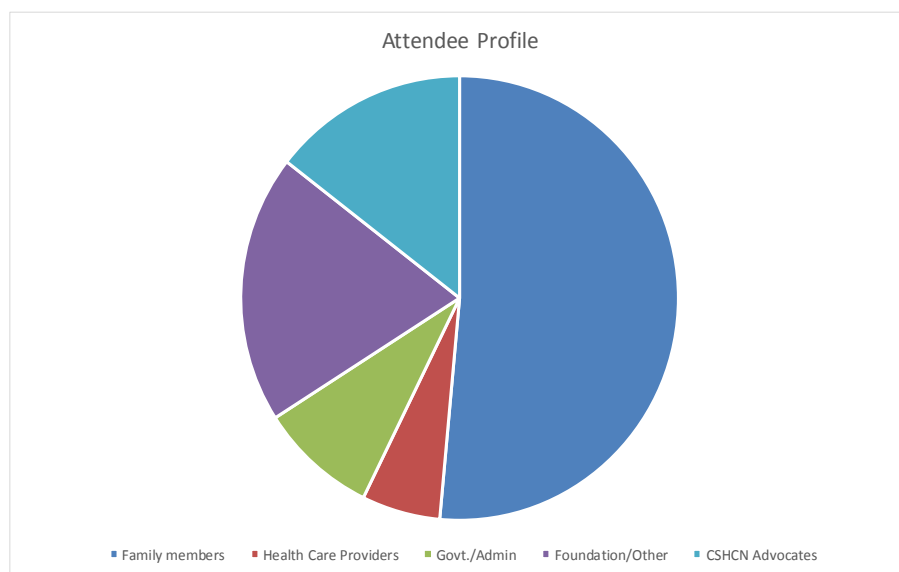
## Panels Spark Discussion

Following the Mental Health panel presentations, summit attendees broke into small facilitated discussion groups which allowed the families to digest and reflect on what they heard, and to identify points they wanted to discuss with their legislators the following day. Their discussions included what they heard that 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 CYSHCN.

*continued on page 4*

# PARTICIPANTS

**138** family members, CYSHCN advocates, government staff, health care providers and legislators attended the Health Summit. In addition, 8 children used the free childcare.



## In evaluation surveys, participants identified the ways the Summit impacted them:\*

- ▶ 93% agreed or strongly agreed that the Summit **increased their knowledge of services and resources for children and youth with special health care needs.**
- ▶ 100% agreed or strongly agreed that they learned **new information about policy issues** that affect families of children and youth with special health care needs.
- ▶ 80% 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.**
- ▶ **95% reported their expectations were met at the Summit.**

\*60 participants completed surveys.



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.

## Legislative Day

On March 15, 57 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 **Tim Shannon**, CA Children's Specialty Care Coalition and **Angela Blanchard** from Political Solutions **who presented key strategies for meeting with legislators. State Senator Mark Leno** followed 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 over 25 legislators and/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 CYSHCN (see p. 9.)







**“There was a great balance of professional, administrative, and actual family voices at this year’s summit! The breadth of information covered was also really wonderful.”**

**“The health summit made me more aware of some services that are available to CYSHCN. There was a lot of helpful info on the CCS redesign that I can take back to my community.”**



**“The summit was amazing! I learned so much and realized how many components play a part in the world of a child with special health care needs.”**

**“This conference opened my eyes to the services available to my son and family. It’s given me the knowledge and courage to continue asking for support.”**



**This was the best health summit I’ve attended so far! The speakers were moving, the participants were so engaged, and the panel topics were excellent. Dr. Pan was particularly inspiring. It was amazing seeing so many parents gathered under one roof speaking the truth to power.**

# HEALTH SUMMIT AGENDA

7:30 - 8:45AM	<b>Registration and Continental Breakfast</b>
8:45 - 9:15AM	<b>Welcome and Overview of Summit</b> Yvette Baptiste, Family Voices of California Council Member and Executive Director of Eastern Los Angeles Family Resource Center  Summit Day Facilitators: Catherine Blakemore, Disability Rights California Ann Kuhns, California Children's Hospital Association Michele Byrnes, Parent and FVCA Project Leadership Graduate
9:10 - 9:15AM	<b>Terry Racciato, Together We Grow</b>
9:15 - 9:30AM	<b>Key Note Speaker: Senator Richard Pan</b>
9:30 - 10:30AM	<b>Medi-Cal Managed Care for Children and Youth with Special Health Care Needs</b> Moderator: Catherine Blakemore, Disability Rights California Greg Buchert, MD, California Health and Wellness Linda Nguy, Western Center on Law and Poverty Tony Maynard, Hemophilia Council, Consumer, and Parent Kelly Hardy, Children Now
10:30 - 10:45AM	<b>Break</b>
10:45 - 12:15PM	<b>The Future of CA Children's Services (CCS): Proposals for Change</b> Moderator and Overview: Laurie Soman, Lucile Packard Children's Hospital and CRISS Jennifer Kent, Department of Health Care Services Yvette Baptiste, FVCA Council Member and Executive Director of Eastern Los Angeles Family Resource Center Kausha King, Parent and FVCA Project Leadership Graduate Ann Louise Kuhns, California Children's Hospital Association Kelly Hardy, Children Now



**12:15 - 1:15PM**

**Lunch**

**1:15 - 3:00PM**

**Mental Health for Children and Youth with Special Needs in CA**

Moderator: Christina Mills, California Foundation for Independent Living Centers  
Diane E. Van Maren, Public Policy Consultant and National Alliance for Mental Illness (NAMI) of California Board Member  
Maggie Roberts, Disability Rights California  
Peter Currie, PhD, Inland Empire Health Plan  
Jenny Kattlove, The Children's Partnership  
Barbara Sheehy, Alameda CCS Mental Health Initiative

**3:00 - 3:15PM**

**Break**

**3:15 - 4:30PM**

**Group Discussion and Report Back**

**5:00 - 5:30PM**

**Closing Remarks & Legislative Day Information**

Ann Kuhns and Michele Byrnes



# DISTINGUISHED SPEAKERS

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

## March 14: Health Summit

Ann Kuhns, California Children's Hospital Association

Barbara Sheehy, Alameda CCS Mental Health Initiative

Catherine Blakemore, Disability Rights California

Christina Mills, California Foundation for Independent Living Centers

Diane E. Van Maren, Public Policy Consultant and National Alliance for Mental Illness (NAMI)

Greg Buchert, MD, California Health and Wellness

Jennifer Kent, California Department of Health Care Services

Jenny Kattlove, The Children's Partnership

Kausha King, Parent and FVCA Project Leadership Graduate

Kelly Hardy, Children Now

Laurie Soman, Lucile Packard Children's Hospital and CRISS

Linda Nguy, Western Center on Law and Poverty

Maggie Roberts, Disability Rights California

Michele Byrnes, Parent and FVCA Project Leadership Graduate

Peter Currie, PhD, Inland Empire Health Plan

Senator Richard Pan, MD

Tony Maynard, Hemophilia

Council, Consumer, and Parent

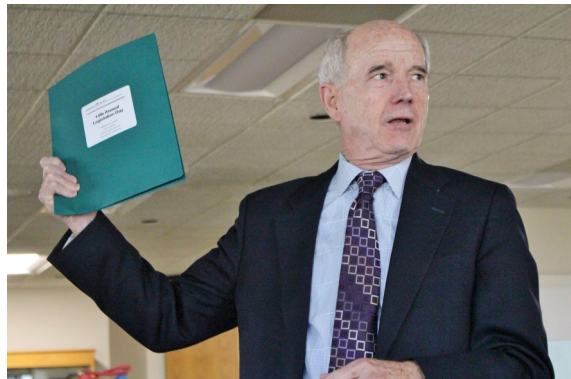
Yvette Baptiste, FVCA Council Member and Executive Director of Eastern Los Angeles Family Resource Center

## March 15: Legislative Day

Tim Shannon, Political Solutions, and California Children's Specialty Care

Angela Blanchard, Political Solutions

Senator Mark Leno (D-San Francisco)





## **FVCA Recommendations for Improving Systems and Services For CYSHCN: March 2016**

Family Voices of California (FVCA) is grateful that our state's finances have stabilized and that the years of catastrophic cuts to health, human services, and education are over. We applaud the Governor and the Legislature — and the state's voters — for taking the necessary steps to keep us on the road to sound financial footing. 2016 offers new opportunities for children and youth with special health care needs (CYSHCN) and their families, such as expansion of Medi-Cal to undocumented children, but there are threats to their health care access, as well. FVCA has identified the following recommendations for improving programs, systems, and services for CYSHCN and their families:

### **Ensure Family/Professional Partnership at All Levels of Decision Making**

- ✓ It is critical that families who are impacted by changes and new programs have input and decision-making opportunities 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.**
- ✓ Families are a necessary and valuable component to state and local health care-related committees and task forces and must be included.
- ✓ Ensure that families are supported to participate at all levels, and are included in developing, monitoring, and evaluating systems changes.
- ✓ State financial support of family-to-family agencies is an essential component to ensure families are informed and educated and supports authentic family involvement in family/professional partnerships.

### **Ensure CYSHCN have Timely Access to Care and Services**

- ✓ California's per capita Medi-Cal expenditures are the lowest in the nation; we must do better in order to strengthen and maintain our Medi-Cal provider network for all Californians, particularly CYSHCN.
- ✓ Restore provider reimbursement reductions to ensure that Medi-Cal has adequate pediatric primary and subspecialty providers, pharmacies, Durable Medical Equipment (DME) and medical supply vendors, in-home nursing, and providers of other critical services.

### **Ensure CYSHCN have Access to Expert Specialty Care and Services**

- ✓ The process of reform of CCS and the possible movement of CYSHCN to Medi-Cal Managed Care should be driven by the needs of the CYSHCN rather than an artificial timetable.
- ✓ 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 are ensured so that CYSHCN are guaranteed to receive the care that they need.
- ✓ Ensure that the essential components of the CCS program, including state quality standards and timely access to appropriate pediatric sub-specialty care, medical case management, and care coordination are maintained for CYSHCN as the state considers changes to the health care delivery system serving children eligible for the program.
- ✓ Create an effective system for the state to maintain and enforce state CCS standards for pediatric subspecialty providers, including hospitals, Specialty Care Centers, and physicians
- ✓ Promote collaboration of state and county CCS to identify and implement program changes to make CCS more efficient, effective, and family friendly and consider continuation of an improved CCS as a real option.

### **Support Developmental Services for CYSHCN and Their Families**

- ✓ Continue the restoration of Regional Center and other developmental services that were part of the enormous budget cuts during the Great Recession.
- ✓ Reimbursement rates for caregivers and service providers have been frozen since 1996, while the cost of living in the state has soared.
- ✓ Approximately \$1 billion have been cut from the Department of Developmental Services since 2008, resulting in the closing of nearly 25,000 state and local support and service providers in the state since 2011.

## **THE FEDERAL MATERNAL CHILD HEALTH BUREAU: SIX CRITICAL SYSTEMS OUTCOMES SET FOR HEALTHY PEOPLE 2020**

- Family/professional partnership at all levels of decision making
- Access to coordinated comprehensive care within a medical home
- Access to adequate private and/or public insurance to pay for needed services
- Early and continuous screening for special health needs
- Organization of community services for easy use
- Youth transition to adult health care, work, and independence

### **CA Today: How are Children and Youth with Special Health Care Needs Faring?**

**There are approximately 1 million children and youth with special health care needs (CYSHCN) in California.**

Family Voices of California is grateful that our state's finances have stabilized and that the years of catastrophic cuts to health, human services, and education are over. 2016 offers new opportunities for CSHCN and their families, such as expansion of Medi-Cal to undocumented children, but there are threats to their health care access, as well.

Compared to children in other states, California's children continue to receive care that is less coordinated and less family-centered, and fails to meet many of the key quality indicators prescribed by the Federal Maternal and Child Health Bureau. **Look where California ranks!**

<b>Where does California rank in the nation in regards to taking care of children and youth with special health care needs (CYSHCN)?</b>	
<b>34<sup>th</sup></b>	CYSHCN who have consistent and adequate health insurance
<b>36<sup>th</sup></b>	CYSHCN receiving transition services to adulthood
<b>46<sup>th</sup></b>	CYSHCN receiving effective care coordination
<b>46<sup>th</sup></b>	CYSHCN with more complex needs receiving comprehensive, family-centered care within a medical home
<b>49<sup>th</sup></b>	Publicly insured CYSHCN receiving care within a comprehensive medical home
<b>50<sup>th</sup></b>	CYSHCN getting needed referrals for specialty care
<b>50<sup>th</sup></b>	CYSHCN with public insurance coverage receiving health care that meets the federal quality standards
<b>50<sup>th</sup></b>	Family/professional partnership at all levels of decision making







## 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 (CYSHCN). 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 CYSHCN and 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 CYSHCN 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.

## COUNCIL MEMBERS

### **San Francisco County**

**Coordinating Office: Support for Families**  
1663 Mission Street, 7th Floor SF, CA 94103  
Phone: 415.282.7494  
Email: [pipmarks@familyvoicesofca.org](mailto:pipmarks@familyvoicesofca.org)  
Contact: Juno Duenas and Pip Marks

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

**Rowell Family Empowerment of Northern California**  
962 Maraglia Redding, CA 96002  
Phone: 530-226-5129  
Email: [wendy.longwell@rfenc.org](mailto: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  
Phone: 310-258-4063; 323-717-7411  
Email: [family@westsiderc.org](mailto: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  
Email: [coordinator@elafrc.net](mailto:coordinator@elafrc.net)  
Contact: Yvette Baptiste

### **Alameda County**

**Family Resource Network**  
5232 Claremont Avenue Oakland, CA 94618  
Phone: 510-547-7322  
Email: [frn@frnoakland.org](mailto: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  
Email: [info@alpharesourcecenter.org](mailto:info@alpharesourcecenter.org)  
Contact: Patty Moore

### **Fresno, Kings County**

**EPU Children's Center**  
4440 North First Street Fresno, CA 93726  
Phone: 559-229-2000 x 193  
Email: [abreedlove@epuchildren.org](mailto:abreedlove@epuchildren.org)  
Contact: Krista Rose and Amy Breedlove



## THANKS TO OUR GENEROUS 2016 HEALTH SUMMIT SPONSORS:



CALIFORNIA  
CHILDREN'S  
HOSPITAL  
ASSOCIATION



Lucile Packard  
Children's Hospital  
at Stanford



CALIFORNIA  
HEALTHCARE  
FOUNDATION



University of California  
San Francisco



Lucile Packard Foundation  
for Children's Health



Valley  
Children's  
HEALTHCARE



# THANK YOU!

## FVCA 2016 Summit Advisory Committee

Catherine Blakemore, Disability Rights California  
Angela Blanchard, Political Solutions  
Michele Byrnes, Parent and FVCA Project Leadership Graduate  
Lisa Chamberlain, MD, Lucile Packard Children's Hospital at Stanford  
Janis Connallon, Children's Defense Fund  
Erin Kelly, Children's Specialty Coalition  
Jenny Kattlove, The Children's Partnership  
Ann Kuhns, California Children's Hospital Association  
Mike Odeh, Children Now  
Christina Mills, California Foundation for Independent Living Centers  
Cindy Claflin, United Advocates for Children and Families  
Kathi Smith, LA County CCS UCEDD  
Kausha King, Parent and FVCA Project Leadership Graduate  
Ann Hall, Parent, FVCA Project Leadership Graduate  
Laurie Soman, CRISS Project and Lucile Packard Children's Hospital

FAMILY  VOICES  
of California

1663 Mission St. 7<sup>th</sup> floor  
San Francisco, CA 94103  
Phone: (415) 282.7494, ext. 123  
Fax: (415) 282.1226

