

FAMILY VOICES of California

13TH ANNUAL
HEALTH SUMMIT
&
LEGISLATIVE DAY
March 16-17, 2015



2015 HEALTH SUMMIT AND LEGISLATIVE DAY: HIGHLIGHTS

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 (CYSHCN). On March 16 2015, FVCA held its 13th 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 2015 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 2015 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 2016; having a better, clearer un-

derstanding of Transition of Care for CYSHCN (Pediatrics to Adult), as well as learning about Medi-Cal ABA services/reimbursements, new state laws for In Home Support Services and how CYSHCN are faring

under the new Covered California laws. 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 125 participants, including 59 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 50 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 caregiving for 6 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 moderators, **Catherine Blakemore, Executive**



Sen Richard Pan and Rocio Smith

Director Disability Rights California and Rocio De Mateo Smith 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 Health Committee, Senator Pan has set a high priority for addressing the health care needs of CYSHCN.

Mara McGrath, from the Children's Regional Integrated Service System (CRISS) Project and Lucile Packard Children's Hospital, facilitated the first panel of expert speakers who addressed specific issues, challenges as well as successful programs in place for transition of care for young adults with special health care needs. The panel consisted of **Jennifer Rienks, PhD**, Family Health

The vision for the 2015 Summit: a world where our children's health care is self determined, family centered, and quality health care is the norm.

Outcomes Project; **Dr. Rachel Ben- sen**, Lucile Packard Children's Hospital; and **Arianna Vaewsorn, Lucille Maniti**, and **Kristen White**, all from Alameda County California Children's Services (CCS).

The second panel of speakers in the morning addressed other health care issues/concerns in California for CYSHCN. **Mike Odeh** from Children Now facilitated the panel. **Karen Fessel**, Autism Health Insurance Project spoke about Medi-Cal's new coverage of Applied Behavioral Analysis for CYSHCN on the Autism spectrum; **Janis Connallon** from Children's Defense Fund addressed the impact that Covered California's Healthcare reform laws has on CYSHCN and **Deborah Doctor**, Lead attorney at Disability Rights California talked about the new In-Home Support Services laws in the state.

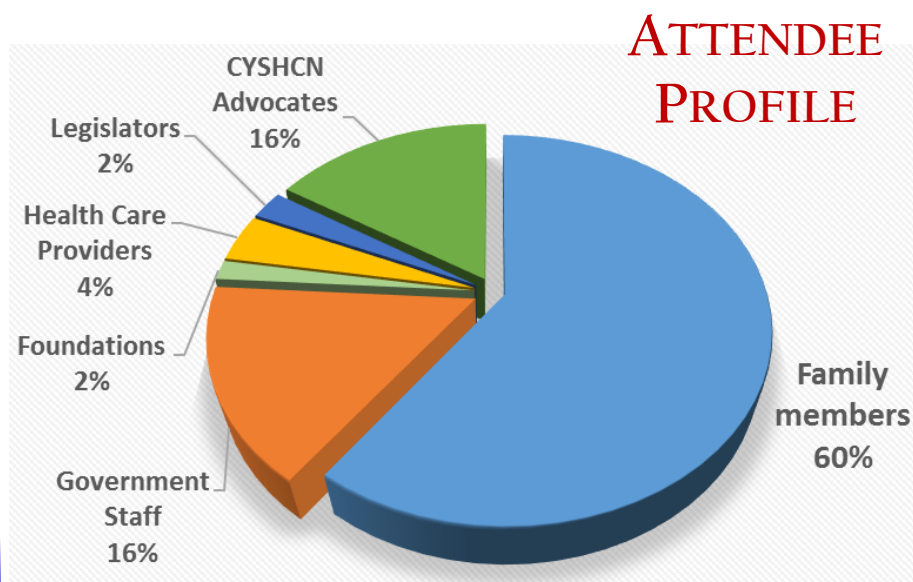
Just before lunch **Secretary Diana Dooley** of California Health and Human Services (HHS) gave a key note address about the CCS carve-out (January 2016) and re-assured the Summit participants that the two main priorities for HHS are to continue to treat the whole child, not just the CCS condition and to look at standards for centers and the providers treating the children. Secretary Dooley said her vision of future is "more health, less treatment." When treatment is needed, it will be in a more coordinated way.

After lunch **Laurie Soman**, **CRISS Executive Director** and Sen-

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PARTICIPANTS

125 family members, CYSHCN advocates, government staff, health care providers and legislators attended the Health Summit. In addition, 6 children used the free childcare.



Evaluation

In their 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.

ior 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 panel consisted of **Lisa Chamberlain, MD** Stanford School of Medicine and Packard Children's Hospital; **Jennifer Rienks, PhD**, Family Health Outcomes Project; **Anastasia Dodson**, Assistant Director for Policy at the Department of Health Care Services; **Katie Schlageter**, Alameda County CCS; **Ann Kuhns**, President, CEO, CA Children's Hospital Association; **Daniel Vasquez**, Support for Families Staff, Parent, FVCA Project Leadership Graduate; and **Kausha King**, CARE, Parent, FVCA Project Leadership Graduate. The panel highlighted specific successes and concerns for the CCS program.

Panels Spark Discussion

Following the CCS panel presentations, all summit

attendees broke into small discussion groups. FVCA Summit Advisory Council members facilitated the conversations. The dis-



Sen. Ed Hernandez

cussion groups 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: 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 children/youth with special

health care needs.

At the end of the day, **State Senator Ed Hernandez** addressed his new bill SB 586 "Kids Integrated Delivery systems" which would allow CCS providers to form systems to integrate primary care with specialty care and treat the whole child not just his or her CCS eligible condition.

State Senator Holly Mitchell ended the day and received a full-house standing ovation for her inspirational keynote address from a legislator's 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 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 17, 53 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** who presented key strategies for meeting with legislators. **State Senator Mark Leno** followed, talking about the new CA



CCS Panel

budget 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 32 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. 10).

"...Just great to be in a room with all these people that are my resources and experts to go to, my network."

"...a good foundation to see the big importance of the advocacy here. It has also provided insight and networking for resources and partnerships."

"...opened my eyes to many situations both positive and negative that have an impact on families that I serve as well as my own children."

"It made me want to participate more and advocate for those who can't for themselves. I would definitely like to return next year."



State Sen Mark Leno



Participant at Legislative Day



Sen. Holly Mitchell and attendees



Laurie Soman and Catherine Blakemore

13TH ANNUAL HEALTH SUMMIT AGENDA

8:00 - 9:00 AM	Registration and Continental Breakfast
9:00 - 9:15 AM	Welcome and Overview of Summit Pip Marks, Family Voices of California Council Manager <u>Summit Moderators:</u> Catherine Blakemore, Executive Director, Disability Rights California Rocio de Mateo Smith, former Executive Director, Area Board 5 on Developmental Disabilities
9:15-9:45AM	Opening Key Note Speaker: State Senator Richard Pan (D-Sacramento)
9:45-10:45 AM	Panel: Transition of Care: (Pediatrics to Adult) Mara McGrath, MPH, Lucile Packard Children's Hospital and CRISS Jennifer Rienks, PhD, Family Health Outcomes Project Dr. Rachel Bensen, Lucile Packard Children's Hospital Arianna Vaewsorn, Alameda County CCS Lucille Maniti, Alameda County CCS Kristen White, Alameda County CCS
10:45-11:00 AM	Break
11:00-12:00PM	"Other Issues/HealthCare Changes" Panel: Mike Odeh, Children Now Karen Fessel, Autism Health Insurance Project Janis Connallon, Children's Defense Fund Deborah Doctor, Disability Rights California
12:00-12:30 PM	Key Note: Secretary Diana Dooley , California Dept. of Health Care Services
12:30-1:15 PM	Lunch

13TH ANNUAL HEALTH SUMMIT AGENDA

1:15-2:45 PM

The Future of CA Children's Services (CCS): Proposals for Change

Laurie Soman, Lucile Packard Children's Hospital and CRISS

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

Jennifer Rienks, PhD, Family Health Outcomes Project

Anastasia Dodson, Department of Health Care Services

Katie Schlageter, Alameda County CCS

Ann Kuhns, President, CEO, CA Children's Hospital Association

Daniel Vasquez, Support for Families Staff, Parent, FVCA Project Leadership Graduate

Kausha King, CARE, Parent, FVCA Project Leadership Graduate

2:45 – 3:00PM

Break

3:00- 4:00 PM

Group Discussion and Report Back

4:00 – 5:00PM

Keynote Speakers:

4:00pm –State Senator Ed Hernandez (D-West Covina)

4:30pm –State Senator Holly Mitchell (D-Los Angeles)

5:00 – 5:30PM

Closing Remarks & Legislative Day Information; Evaluations



Secretary Diana Dooley



DISTINGUISHED SPEAKERS

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

March 16: Health Summit

Catherine Blakemore, Executive Director, Disability Rights California

Dr. Rachel Bensen, Lucile Packard Children's Hospital

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

Janis Connallon, Children's
Defense Fund

Deborah Doctor, Disability
Rights California

Anastasia Dodson, Department
of Health Care Services

Secretary Diana Dooley,
Department of Health Care
Services

Karen Fessel, Autism Health
Insurance Project

State Senator Ed Hernandez (D-
West Covina)

Kausha King, CARE, Parent, FVCA
Project Leadership Graduate

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

Lucille Maniti, Alameda County
CCS

Mara McGrath, MPH, Lucile
Packard Children's Hospital and
CRISS

State Senator Holly Mitchell (D-
Los Angeles)

Mike Odeh, Children Now

State Senator Richard Pan (D-
Sacramento)

Jennifer Rienks, PhD, Family
Health Outcomes Project

Katie Schlageter, Alameda
County CCS

Rocio de Mateo Smith, Retired
Executive Director, Area Board 5
on Developmental Disabilities

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

Arianna Vaewsorn, Alameda CA
Children's Services

Daniel Vasquez, Support for
Families Staff, Parent, FVCA
Project Leadership Graduate

Kristen White, Alameda County
CCS

March 17: Legislative Day

Tim Shannon, Political Solutions,
CA Children's Specialty Care

State Senator Mark Leno (D-San
Francisco)



KEY ISSUES for California Families of Children and Youth with Special Health Care Needs March 2015

California's health care system is inadequate to meet the needs of children and youth with special health care needs (CYSHCN) and their families. Compared to children in other states, California's children continue to receive care that is less coordinated, less family-centered, and fails to meet many of the key quality indicators prescribed by the Federal Maternal and Child Health Bureau.

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

Clearly, there is much to be done!



FVCA: ADDRESSING KEY ISSUES

The U.S. Maternal Child Health Bureau has six critical systems outcomes set out in the
Healthy People 2020
National Health Objectives:

- ◇ 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

With MCHB critical systems outcomes in mind, FVCA has identified the following key solutions for the issues facing California children and youth with special Health care needs (CYSHCN) and their families:

► **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 and supported to participate 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 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.**

► **Access to Coordinated Comprehensive Care within a Medical Home –**

Strengthen Medi-Cal Program's Capacity to Serve CYSHCN

- 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.



FVCA: ADDRESSING KEY ISSUES

► 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 subspecialty 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 are 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. California has been challenged by the federal government for not providing adequate and timely identification of children at risk. California should continue to fund family resource centers to provide child-find services for regional centers, to assist families in obtaining services from regional centers and community agencies, and to provide support to families with at-risk children.

► 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.
- CA must create a state-specific website as a transition resource for patients, families, providers and those serving them.

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.





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