

# FAMILY VOICES of California

## 15th Annual Health Summit And Legislative Day February 27-28, 2017



# HEALTH SUMMIT HIGHLIGHTS

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). On February 27, 2017 FVCA held its 15th 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 2017 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 2017 Summit Advisory Committee, made up of families and professionals, (see p. 12) worked together to plan the day. The Summit's objectives included enabling families, health care providers, and advocates for CYSHCN to learn about the changes to California Children's Services (CCS) with the Whole Child Model (WCM); having a better, clearer understanding of the Medi-Cal 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 185 participants. 98 family members represented diverse areas of the state from Humboldt County in the north to San Diego in the south. 87 professionals

**"This is my third year attending the Summit — as before, I am educated, motivated, & ready to advocate."**

attended, including staff from government agencies, health care providers, foundations, and other health-related organizations.

For the first time, this year's Summit featured a dedicated programming track for youth, which was organized and led by youth and young adults with disabilities in partnership with YO! Disabled & Proud.

Thanks to the support of generous sponsors (see p. 11), FVCA provided breakfast and lunch for all attendees, as well as free caregiving for 9 children of attending families.

## Speakers Set the Tone

This year's Summit featured many experts in the field of healthcare pertaining to CYSHCN.

The Summit moderators, Catherine Blakemore, Executive Director Disability Rights California, and Kausha King, a parent and FVCA Project Leadership graduate, set the tone and enhanced the day with thoughtful insights.

The Summit was opened with FVCA presenting an award to Dr. Ed Schor and the Lucile Packard Foundation for Children's Health (LPFCH) for all their dedicated work and advocacy on behalf of CYSHCN, as well as their continued generous support for FVCA's project leadership program.

Jennifer Kent, Director of DHCS, opened the CCS/WCM panel discussion by giving a general overview. Kelly Hardy expertly moderated the CCS panel of speakers which opened with Laurie Soman, CRISS Executive Director and Senior Policy Analyst at Lucile Packard Children's Hospital. Laurie provided an overview of SB 586, highlighting key provisions of the bill that are in place to protect families, the CCS Advocates Coalition, and the future of CCS. Jacey Cooper from DHCS covered how the WCM will engage with families; Mira Morton, Director of Government Relations for CA Children's Hospital Association, spoke about the importance of family advocacy and how families can get involved. Brianna Lierman from Local Health Plans of CA shared the county health plans' perspective and their plans for WCM implementation and family engagement (Family Advisory Councils). Donnell Kenworthy, Parent Advocate, talked about her family's personal experiences raising DJ, her son who has complex health care needs. She also talked about the critical importance of CCS services DJ has been receiving since birth and her WCM concerns.



The second session in the morning addressed Mental Health for CYSHCN in California. Kathryn Smith, Children’s Hospital Los Angeles, moderated the panel. Katie Hornberger from Disability Rights California covered insurance for mental health services; how to request services, denials, and appeals and the intersection of Regional Centers and insurance. Dr. Clayton Chau, Regional Executive Medical Director at the Institute for Mental Health & Wellness, talked about EPSDT for children under 21 covered by Medi-Cal and Behavioral Health Models of Care and family-focused integrated care models. Kristen Slater from Beacon Health Options covered Medi-Cal Managed Care mental health benefits and responsibilities as well as telehealth as a possible solution for psychiatric consultations. Dr. Heather Huszti spoke about the Children’s Hospital of Orange County’s new inpatient psychiatric ward for children with mental illness—a model of care that promises to work well. Dr. Huszti also talked about mental health outpatient services in the community. And finally, Olga Maldonado and her daughter Magaly gave a very moving presentation about their own experiences with mental illness and the processes trying to get a correct diagnosis and treatment.

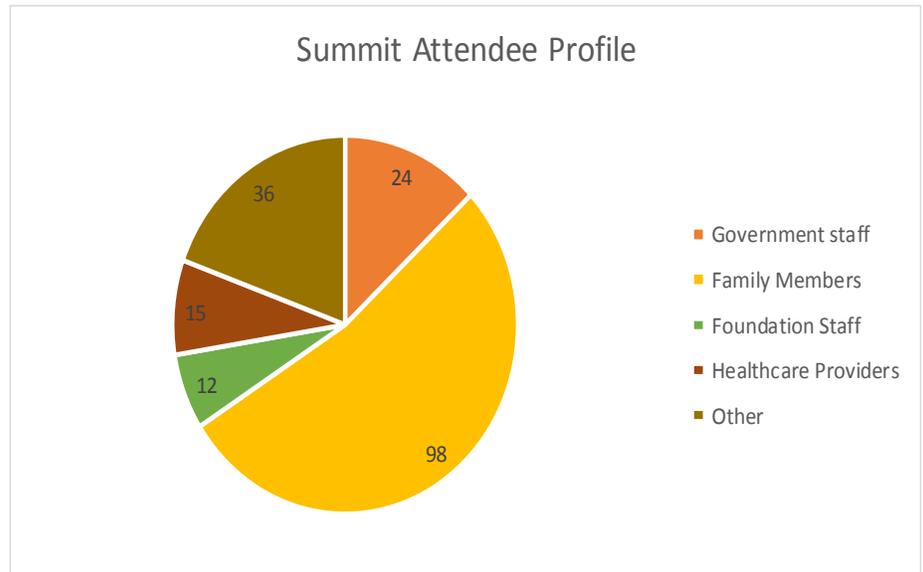
During lunch, FVCA presented an award to Senator Ed Hernandez for all his work on the CCS/WCM legislation - SB 586. Ling Liu from LPFCH facilitated a Q and A with Melvin Mar the Executive Producer of the new television series, *Speechless*, which portrays a family with a child with special needs.

After the lunch break, Anne Hall, parent and Project Leadership graduate, moderated the Medi-Cal panel. Elizabeth Zirker from Disability Rights California talked about IHSS, protective services, para medi-

*continued on page 4*

## SUMMIT PARTICIPANTS

**185** family members, CYSHCN advocates, government staff, health care providers, and legislators attended the Health Summit. In addition, 9 children used the free childcare.



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

- ▶ 90% agreed or strongly agreed that the Summit **increased their knowledge of services and resources for children and youth with special health care needs.**
- ▶ 90% agreed or strongly agreed that they learned **new information about policy issues** that affect families of children and youth with special health care needs.
- ▶ 85% 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.**
- ▶ 89% reported **their expectations were met at the Summit.**

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cal services, EPSDT, nursing shift low rates, barriers to in-home nursing, and issues for families who have multiple children with special needs. Sherri Sager, Lucile Packard Children's Hospital, provided a perspective as an advocate for medically fragile children and presented on the challenges in finding in-home nursing for pediatric patients being discharged, the lack of skilled nurses to do in-home nursing, and low reimbursement rates resulting in unnecessarily long hospital stays until nurses become available. Gayle Mathe, CA Dental Association talked about access to dental care especially for CYSHCN and the challenges that are currently occurring: lack of pediatric dental providers especially in rural areas, low reimbursement rates, dental transformation initiative, and Prop 56 funds with regards to dental care under Medi-Cal. To end the panel, Larene Pare gave her parent perspective on her family's challenges and successes with in-home nursing for her daughter Niara who is now 20 years old.

**“Such good, practical information presented — not a “show and tell” like many conferences, but action steps that participants can take to influence change.”**

islator the next day to help them understand health care for their child and other CYSHCN.

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

## Legislative Day

On Tuesday February 28, over 65 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 Richard Pan and his District Director Claire Conlon spoke about the Senate Select Committee on Children with Special Needs which Senator Pan

chairs. They both encouraged participants by reminding them that their voices are important and they deserve to be heard. 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.



## Panels Spark Discussion

Following the Medi-Cal panel presentations, summit attendees broke into small facilitated discussion groups which allowed 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 focused on (1) topics presented by panels and speakers that might benefit their child's health care, (2) current issues that might have a negative impact on their child's health care, and (3) key points that they wanted to tell their leg-



# 2017 HEALTH SUMMIT AGENDA

- 8:30 - 9:00AM **Welcome and Overview of Summit**  
**Patty Moore**, Family Voices of California, Alpha Resource Center
- Summit Day Facilitators:**  
**Catherine Blakemore**, Disability Rights California  
**Kausha King**, Parent, FVCA Project Leadership Graduate
- 9:00 - 9:15AM **Key Note Speaker: Senator Richard Pan**
- 9:15 - 10:30AM **The Future of CA Children’s Services and the Whole Child Model:**  
**Jennifer Kent**, CA Department of Health Care Services  
**Panel:**  
**Moderator: Kelly Hardy**, Children Now  
**Laurie Soman**, CRISS Project, Lucile Packard Children’s Hospital  
**Jacey Cooper**, CA Department of Health Care Services  
**Ginger MacGowan and Donnell Kenworthy**, Parent Perspective  
**Mira Morton**, CA Children’s Hospital Association  
**Brianna Lierman**, Local Health Plans of California  
**Q and A**
- 10:30 - 10:40AM **Memorial tribute to Erin Aaberg Givans**  
**Tim Shannon**, Children’s Specialty Care Coalition
- 11:00 - 12:00PM **Mental Health for Children and Youth with Special Needs in CA**  
**Moderator: Kathryn Smith**, Children’s Hospital Los Angeles  
**Katie Hornberger**, Disability Rights California  
**Clayton Chau, MD, PhD**, Institute for Mental Health and Wellness  
**Kristen Slater**, Beacon Health Options  
**Heather Huszti, PhD**, Children’s Hospital Orange County  
**Olga and Magaly Maldonado**, parent and teen perspective
- 12:00 - 12:30PM **Proposed changes to Medicaid Block Grants, ACA, Title V funding & how these changes might affect Children with Special Care Needs in CA**  
**Edwin Park**, VP for Health Policy, Center on Budget and Policy Priorities  
**Sandra Shewry**, CA Healthcare Foundation
- 12:30 - 1:30PM **Lunch:**  
**Senator Ed Hernandez**, Senate District 22
- 1:30 - 3:00PM **Medi-Cal for Children with Special Health Care Needs**  
**Moderator: Anne Hall**, Parent, FVCA Project Leadership Graduate  
**Elizabeth Zirker**, Disability Rights California  
**Sherri Sager**, Lucile Packard Children’s Hospital at Stanford  
**Gayle Mathe**, CA Dental Association  
**Larene Pare** – Parent perspective  
**Q and A**
- 3:15 - 4:30 PM **Group Discussion and Report Back**
- 4:30 - 5:00PM **Keynote Speaker: Senator Holly Mitchell**
- 5:00 - 5:30PM **Closing Remarks & Legislative Day Information**  
**Evaluations:**  
**Catherine Blakemore and Kausha King**

## DISTINGUISHED SPEAKERS

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

**Catherine Blakemore**, Disability Rights California

**Clayton Chau, MD, PhD**, Institute for Mental Health and Wellness

**Jacey Cooper**, DHCS

**Anne Hall**, Parent, FVCA Project Leadership Graduate

**Kelly Hardy**, Children Now

**Senator Ed Hernandez**, Senate District 22

**Katie Hornberger**, Disability Rights California

**Heather Huszti, PhD**, Children's Hospital Orange County

**Erin Kelley**, Children's Specialty Care Coalition

**Jennifer Kent**, DHCS

**Donnell Kenworthy**, Parent Advocate

**Kausha King**, FVCA Project Leadership Graduate

**Brianna Lierman**, Local Health Plans of California

**Olga and Magaly Maldonado**, Parent and Teen advocates

**Melvin Mar**, Speechless

**Gayle Mathe**, CA Dental Association

**Senator Holly Mitchell**, Senate District 30

**Mira Morton**, CA Children's Hospital Association

**Larene Pare**, Parent advocate

**Edwin Park**, Center on Budget and Policy Priorities

**Sherri Sager**, Lucile Packard Children's Hospital at Stanford

**Tim Shannon**, Children's Specialty Care Coalition

**Sandra Shewry**, CA Healthcare Foundation

**Kristen Slater**, Beacon Health Options

**Kathryn Smith**, Children's Hospital Los Angeles

**Laurie Soman**, CRISS Project, Lucile Packard Children's Hospital

**Elizabeth Zirker**, Disability Rights California



"I was humbled and energized by the amazing families and dedicated professionals."

# YOUTH HEALTH TRANSITION SUMMIT AGENDA

- 7:30 - 8:30AM **Registration and Continental Breakfast**
- 8:30 - 9:00AM **Welcome and Overview of Summit**  
**Patty Moore**, Family Voices of California Council Member, Alpha Resource Center
- Youth Track Facilitator:**  
**Christina Mills**, CA Foundation for Independent Living Centers
- 9:15- 10:40AM **Youth Track: Moving from Youth to Adult Healthcare Systems**
- 10:40 – 11:00AM **Break**
- 11:00 - 12:30PM **Youth Open Discussion**
- 12:30 -1:30PM **Lunch:**  
**Senator Ed Hernandez**, Senate District 22
- 1:30 - 3:00PM **Youth Panel: My Healthcare Transition Experience**
- 3:00 - 3:15PM **Break**
- 3:15 - 4:30 PM **Youth Track: Planning My for My Own Healthcare Transition & Preparing for Legislative Visits**
- 4:30 - 5:00PM **Keynote Speaker:**  
**Senator Holly Mitchell**
- 5:00 - 5:30PM **Closing Remarks & Legislative Day Information**  
**Evaluations:**  
**Catherine Blakemore and Kausha King**



**“Best Summit ever! Very organized and the flow of information provided a seamless stream. Loved the youth track!”**



# RECOMMENDATIONS FOR PRESERVING AND STRENGTHENING SYSTEMS OF CARE FOR CYSHCN IN CA: 2017

Family Voices of California-- representing more than 20,000 families of CYSHCN across the state-- is grateful that our state's finances have stabilized and that catastrophic cuts to health, human services, and education are behind us. 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. While the state financial picture has improved significantly, we have longstanding concerns about the organization of existing service systems for CYSHCN and the ways they do, or do not, serve our children and families. FVCA has identified several key issues for CSHCN and their families as we confront these challenges, both new and longstanding, beginning with the overarching goal of protecting our existing child health services:

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

**Families' voices must be heard.** It is critical that families who will be impacted by changes and new programs have input and a decision-making role in planning and implementation of any changes that affect them and their children. FVCA members are eager to participate.

**The state must ensure that families are able to participate at all levels of engagement and are included in developing, monitoring and evaluating systems changes.** State financial support of family-to-family agencies is an essential component to ensure that families are informed and educated and to enable authentic family involvement in family/professional partnerships.

## **Ensure that CYSHCN Have Timely Access to Quality Primary and Specialty Care and Related Services**

**Restore provider reimbursement reductions and explore other strategies to ensure that Medi-Cal has adequate pediatric primary and sub-specialty providers, mental and behavioral health service providers, pharmacies, DME and medical supply vendors, and in-home nursing providers.** 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.

## **Strengthen California Children's Services Program (CCS)**

**The state must maintain the essential components of CCS, including state quality standards, statewide network of certified providers, and timely access to appropriate pediatric sub-specialty care and medical case management.**

California Children's Services (CCS) ensures that 180,000 children with complex or potentially disabling medical conditions have timely access to high-quality, often life-saving pediatric care. In addition, the CCS quality standards drive our state's regionalized system of pediatric care for *all* children.

## **Ensure that the state maintains and supports the CCS infrastructure required to update and enforce 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 CYSHCN and that there is strong family engagement in the process as the state moves to implement CCS redesign in 21 County Organized Health System (COHS) counties.

## **Promote collaboration of state and county CCS with families and providers to identify and implement program changes throughout the state to make CCS services more efficient, effective, and family-friendly.**

It is vitally important for CYSHCN that CCS program standards remain current with the latest medical information and that CCS services are as efficient and family-friendly as possible. These goals require investment in the program at the state and local levels. A number of county CCS programs already have launched quality improvement initiatives addressing efficiency and family-friendliness and many of these initiatives are appropriate for replication elsewhere in the state. We urge the state to work with counties, families and providers to implement evidence-based initiatives at the state and local levels.

**In addition, there are substantial threats to health care access for all children, particularly CYSHCN, as we face potentially devastating policy changes and budget cuts at the federal level.**

## **Maintain Access to Health Care for All Children -- Protect Medi-Cal, EPSDT, and Covered CA**

**Our Medi-Cal program must be maintained for children and youth, regardless of what changes are made to Medicaid structure and funding at the federal level.** 5.6 million children-- 60% of our state's children-- receive their health care through Medi-Cal, including many CYSHCN.

**EPSDT must be retained as the gold standard for children's health benefits under Medi-Cal.** EPSDT (Early and Periodic Screening, Diagnosis and Treatment) is the federal Medicaid children's benefit that ensures that children receive a broad array of health services and that the child's physician determines whether treatment is medically necessary. EPSDT is vital to the health and well-being of all Medi-Cal-eligible children, especially CYSHCN.

## **The state must support the ACA and its protections for CYSHCN and maintain a strong Covered California program.**

The Affordable Care Act contains critically important provisions for CYSHCN such as the elimination of exclusions for pre-existing conditions and of annual and lifetime caps on coverage. More than 28,000 children receive their health coverage via Covered California; 70% have subsidized premiums.

# PROTECTING SYSTEMS AND SERVICES FOR CYSHCN AT THE FEDERAL LEVEL: FEBRUARY 2017

The Medicaid program is critical for children and youth with special health care needs (CYSHCN). Medicaid provides an array of medical services and long-term services and supports, many of which are not covered by private insurance. Without Medicaid, these benefits would not be accessible or affordable for families with CYSHCN. EPSDT (Early and Periodic Screening, Diagnosis and Treatment) is the federal Medicaid children's benefit that ensures that children receive a broad array of health services and that the child's physician determines whether treatment is medically necessary. EPSDT is vital to the health and well-being of all Medi-Cal-eligible children, especially CYSHCN.

## Reject Restructuring of Federal Medicaid Financing

Congress is considering proposals to radically restructure Medicaid by changing the program to a block grant or "per capita cap". These proposals would cut federal Medicaid funding for states like California, with the cuts growing larger each year. These cuts could be even larger if California experiences higher-than-expected enrollment or higher-than-anticipated medical costs. To compensate, California would either have to contribute much more of its own funding or make severe cuts to Medi-Cal eligibility, benefits and provider and plan payment rates.

These cuts would mean there will be fewer people covered under Medi-Cal with less access to needed care. CYSHCN would be particularly at risk because they are more likely to need Medicaid-covered long-term services and supports (LTSS). Children who require LTSS have average Medicaid costs 12 times higher than other children.

## Maintain Federal Medicaid Standards, including EPSDT, to Ensure Access to Care and Services

CYSHCN receive needed health and LTSS under Medi-Cal because of the EPSDT benefit in Medicaid that ensures that all children receive needed screenings and treatment, even if some services are not otherwise covered by Medicaid.

Medicaid block grants can eliminate or weaken existing federal requirements for state Medicaid programs related to eligibility and benefits. As a result, states could be given the flexibility to no longer provide EPSDT to children on Medicaid, including CYSHCN. States may also be given the flexibility to no longer enroll everyone who is eligible or to impose waiting lists or charge premiums, deductibles and co-payments that beneficiaries cannot afford, leaving families uninsured or no longer able to access needed care because of the cost.

## Retain the Affordable Care Act's Coverage Expansions and Protections

The Affordable Care Act includes many provisions that are critically important for CYSHCN, such as the elimination of exclusions from coverage because of pre-existing conditions (every CYSHCN has one of those) and elimination of annual and lifetime limits on what insurance will pay for (CYSHCN with expensive conditions could hit their annual cap on expenses in a few months and their lifetime cap in a few years).

The number of children without health insurance fell with the implementation of the Affordable Care Act's Medicaid expansion and premium subsidies for families to buy coverage through the health exchange. (Covered California is our state exchange.) This was due partly to greater outreach and enrollment efforts, but also because research shows that expanding coverage to parents of low-income children increases family willingness to enroll their children in Medicaid and to use health services.

## Support Funding Extension for the Children's Health Insurance Program (CHIP)

California uses federal CHIP funds to provide coverage through Medicaid for children in families with slightly higher incomes but the program runs out of federal funding starting on October 1. Congress should extend federal CHIP funding to ensure that children, including CYSHCN, do not lose coverage or lose access to needed services like EPSDT.



**"I felt part of a larger network of people who care about my child and children like her. It felt so good to talk to people who 'get it.' I learned strategies to interact with my legislators. I felt empowered!"**



**"I was impacted in many ways: from seeing the daily struggle families of children with intellectual disabilities have, but the many challenges of the medically fragile, and those families that have both."**



**"The Summit was a wonderful experience: tons of knowledge, experience sharing— so beneficial. It made a great impact."**



**"This was my first Summit and I was so impressed and inspired by the work. It was one of the most enjoyable and exciting conferences I have attended in a long time."**



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