

Project Leadership Alumni Meeting

Alhambra, California
October 12, 2019

Ali Barclay

Family Engagement Manager

Family Voices of California

Welcome

Yvette Baptiste

East Los Angeles Family Resource Center

FAMILY VOICES of California

FVCA is a statewide collaborative of locally-based, parent-run family resource centers working to ensure quality health care for children and youth with special health care needs.

2020 Health Summit & Legislative Day

Save the Date | March 15-17, 2020

Holiday Inn, 300 J Street, Sacramento

FREE for families

\$75 suggested donation for professionals

*Join us to hear from experts and build relationships with professionals
and legislators at the State Capitol.*

Summit Day 1

(Families, Caregivers, and Youth Only)

Sunday, March 15th

Summit Day 2

Monday, March 16th

Legislative Day

Tuesday, March 17th



Who should attend the Summit?

Parents and caregivers

Youth with special health care needs

Health care providers, agencies, organizations and advocates

Policymakers and staff

Questions? Contact Pip Marks: pipmarks@familyvoicesofca.org

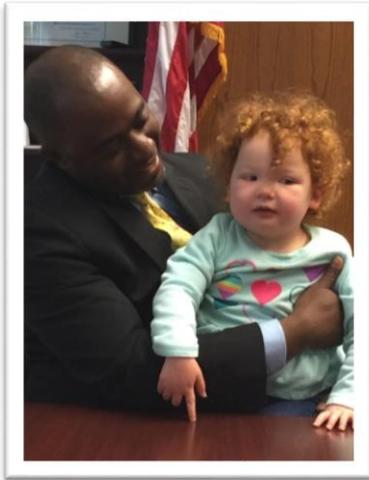
Project Leadership Overview and Preview

Elaine Linn

Project Leadership Manager
Family Voices of California

Family Voices of California

- ❑ California's Family to Family Health Information Center
- ❑ Statewide collaborative of family run centers working to improve access to quality care for children/youth with special health care needs (CYSHCN)



HRSA
Health Resources & Services Administration

 **Lucile Packard Foundation**
for Children's Health

About Project Leadership

- ❑ Preparing and engaging families to impact health policies for CYSHCN
- ❑ Moving from individual to systems advocacy
- ❑ Working toward family representation at *all levels of community and government*

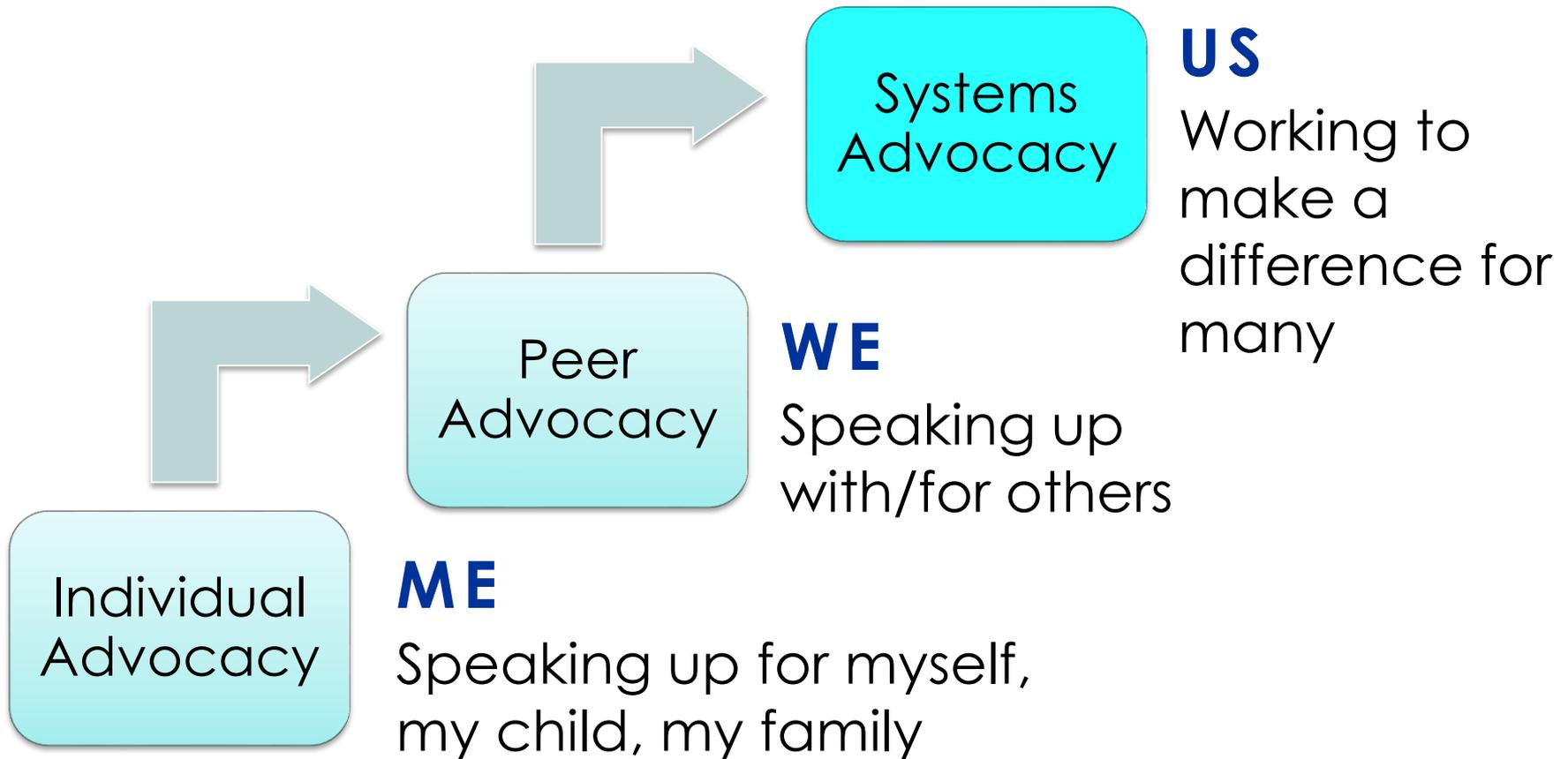
103 Trainers **59** Orgs **280+** Graduates **5** States

Project Leadership in California

- Current Participation
- 2019 Expansion Areas
- 2020 Expansion Areas



Changing Scope and Focus



Skills + Knowledge + Experience + Opportunity = CHANGE

- Confident they can tell their child's story to inform decisionmakers **99%**
- Use their skills on work with committees, boards, etc. **89%**
- Participated on a group focused on children with special health care needs/disabilities **65%**
- Reported a policy or systems change or improvement in the past year **31%**
- Project Leadership training and activities assisted them in their job or led directly to their job.* **59%***

*63% report having a paying job.

What are YOU doing?

1. How have you engaged in systems level advocacy or leadership?
2. What could you do in the next 6-12 months to improve health policies/systems?

- Committee
 - Board
 - Elected official letter/call
 - Elected official meeting
 - Public comment
 - Town Hall
 - Presentation
 - Run for office
 - Other?
-



A Children's Health Policy Update

October 12, 2019
FVCA Project Leadership Alumni Event
Alhambra, CA

Mike Odeh, Director of Health Policy
modeh@childrennow.org



Imagine if every child had the opportunity to reach their full potential.

We are the only organization focused on generating the power to transform children's advocacy and create the needed change for kids.

We are employing proven advocacy strategies to make this change possible:

1 Full Coverage of the Issues

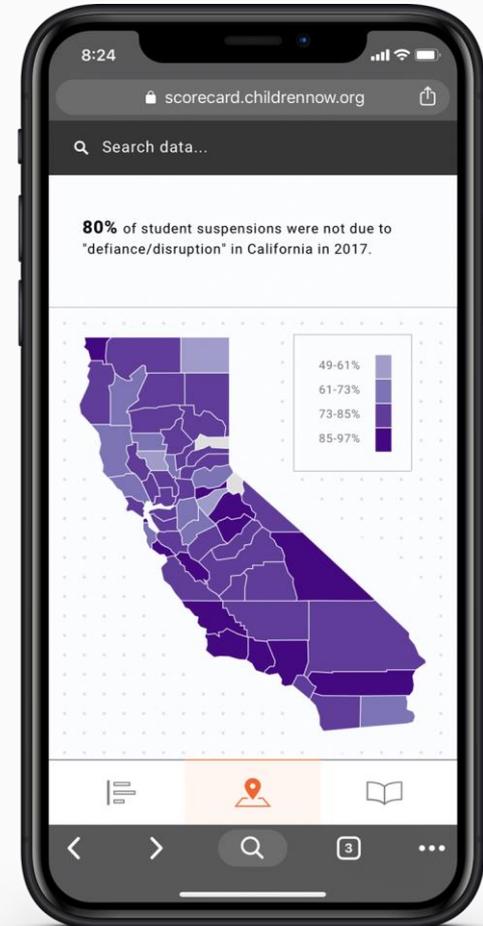
2 Deep Research & Policy Expertise

3 Two-Word Messaging

4 Outside Grassroots Pressure

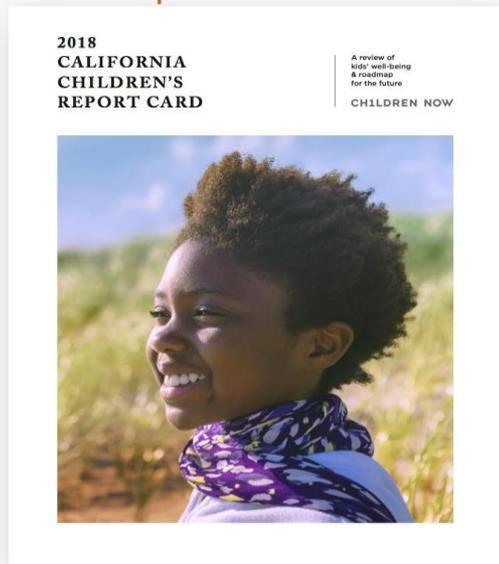
2018-19 California County Scorecard of Children's Well-Being

An interactive tool for tracking key indicators and mapping county-level data of child well-being across counties, over time, and by race and ethnicity.



2018 California Children's Report Card

A review of kids' well-being & roadmap for the future.



Education

Infant & Toddler Care (D+)

Preschool & Transitional Kindergarten (B)

Early Learning Workforce Compensation & Training (C-)

Education for Dual Language & English Learners (D+)

TK-12 Funding (C-)

Academic Outcomes (D)

STEM Education (C)

Teacher Pipeline, Preparation, & Placement (D+)

School Climate & Discipline (B-)

Chronic Absence (B-)

Afterschool & Summer Learning Programs (B-)

Access to Higher Education (C)

Health

Developmental Screenings (C-)

Home Visiting (D+)

Health Insurance (A)

Health Care Access & Coordination (C-)

Mental Health & Building Resilience (D+)

Oral Health Care (C-)

School-Based Health Services (D+)

Food Security (C-)

Child Welfare

Child Abuse & Neglect Prevention (D)

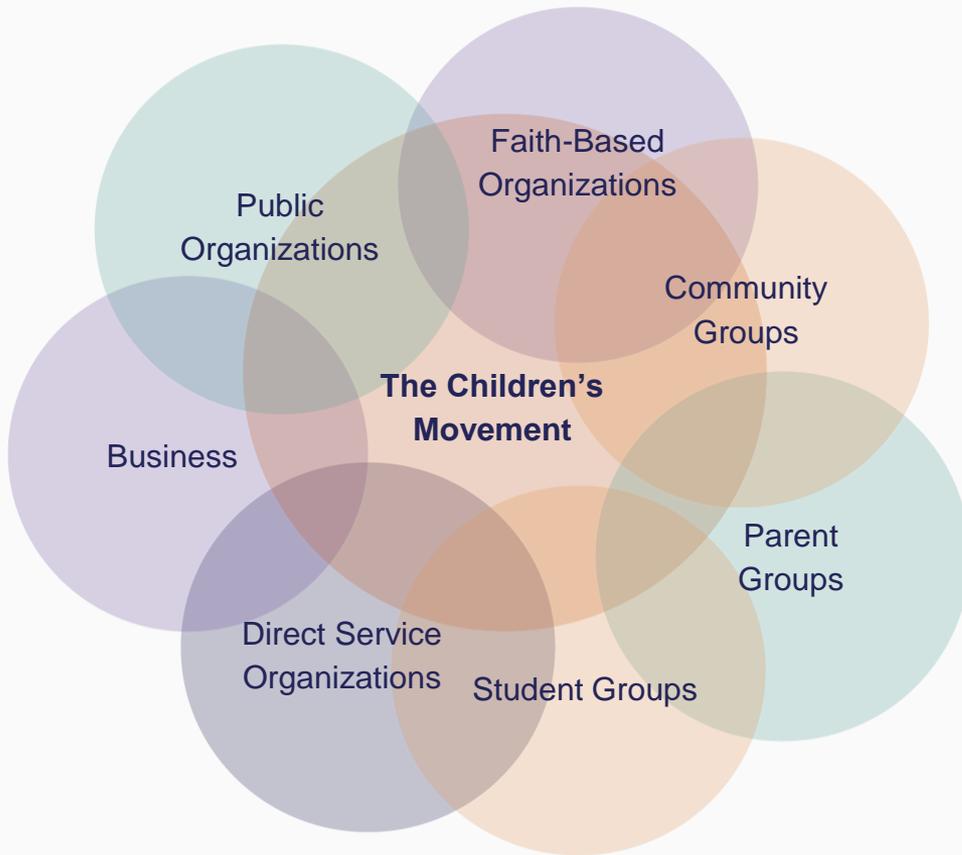
Placement Stability & Permanent Connections (C)

Health Care for Kids in Foster Care (C-)

Education Support for Students in Foster Care (D+)

Youth Justice (D)

Outside Grassroots Pressure: The Children's Movement™



Examples of more than 3,000 Members across California



Children's Health in California: 2019-20 Budget & Legislative Update

- *By Jan. 10th*: Governor releases budget proposal
- Legislature holds hearings
- *By May 14th*: Governor releases revised proposal (May Revise)
- *By June 15th*: Legislature must send budget to Governor
- *July 1st*: Beginning of state fiscal year
- Other legislation had to pass by *September 13th*, and the Governor has until *October 13th* to sign or veto.
- Find additional state budget explainer at the California Budget & Policy Center:
 - <https://calbudgetcenter.org/resources/dollars-and-democracy-a-guide-to-the-state-budget-process-4/>

Final FY 2019-20 Budget: Health Coverage

- **Health coverage for young adults:** \$74.3 million for an expansion of full Medi-Cal coverage for adults aged 19 through 25 regardless of immigration status. This expansion, set to begin January 2020, is expected to cover 90,000 undocumented young adults, and builds on the successful expansion of Health4All Kids.
- **Affordability for health coverage:** An additional \$450 million over three years; \$10 million per year will be used to provide state subsidies to individuals below 138 percent of the federal poverty level and the remaining funds will be used to provide first-in-nation assistance subsidies (through Covered California) to individuals between 400 and 600 percent of the FPL.
- **Health care navigation:** \$60 million (\$30 million GF) in one-time funding through counties to support health enrollment navigators over two years.

Final FY 2019-20 Budget: Health Access

- **Asthma preventive services:** A one-time \$15 million investment to fund asthma preventive and environmental remediation services for kids and adults with poorly controlled asthma on Medi-Cal by expanding access to trained community health workers.
- **Screening for developmental delays and trauma:** \$105 million (\$52.5 million one-time Prop 56 funding) for developmental and trauma screenings and \$50 million (\$25 million Prop 56 one-time funding) for provider training to deliver trauma screenings in Medi-Cal.
- **Value-based payments in Medi-Cal:** \$544.2 million (\$250 million Proposition 56 funds and \$294.2 million federal funds) for the Value-Based Payments Program to pay providers for better health care delivery, with components specifically focused on behavioral health integration, early childhood health, and prenatal/postpartum care.

- **Medi-Cal provider rates and loan repayments:** Significant Proposition 56 funding for supplemental payments & rate increases for Medi-Cal physicians, dental, family planning services, including \$4 million for payments to pediatric facilities and \$2 million for pediatric hospital-based physician services. In addition, \$120 million from Prop. 56 funds will be used for additional awards in the Physicians and Dentists Loan Repayment Program. These provisions sunset in December 2021.
- **Voluntary, evidence-based home visiting:** An unprecedented investment (via a mix of state general funds, TANF dollars and Medicaid Title XIX funds) in voluntary evidence-based home visiting, including expansions of the newly created CA Dept. of Social Services CalWORKs Home Visiting Initiative in 44 counties across California; for the CA Dept. of Public Health California Home Visiting Program in 23 counties.

- **Preventive care outreach campaign for children in Medi-Cal:** \$4 million in Federal and State General Fund in 2019-20 to conduct an initial mailing and phone campaign by January 1, 2020. The campaign would include consultation with stakeholders on development of letters and call scripts. Managed care plans would be responsible for calling beneficiaries. An additional \$10 million for a contract with an independent consultant to conduct surveys of beneficiaries, design outreach materials, engage with stakeholders, and create an outreach campaign recommendations report.



IMMEDIATE ADVOCACY OPPORTUNITY: Is this notice helpful and informative to parents?

[Date]

Important Information About Preventive Care Services Through Medi-Cal

Dear Medi-Cal Beneficiary,

Please read this letter for important information about your or your child's health care.

You are getting this letter because you or your child can get preventive care services such as Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services through Medi-Cal.

Who is eligible for preventive care services?

Infants, children, and youth up to age 21 with full-scope Medi-Cal are able to get preventive care and screening services at no cost.

What are preventive care services?

These services are available to make sure that infants, children and youth under age 21 get age appropriate preventive care, like screenings for medical, dental, vision, hearing, mental health, and substance use disorders. You or your child can also get developmental services, specialty care and vaccinations to keep you healthy. Medi-Cal covers screening services (including lead blood level assessment) any time there is a need for them, even if it is not during your regular check-up. All preventive care and screening services are at no cost to you.

Check-ups and screenings are important to help the health care provider find problems early. When a problem is found during a check-up or screening, Medi-Cal covers the care needed to fix or help any physical or mental health problem. The doctor, dentist, other health care provider, county Child Health and Disability Prevention program (CHDP), or county mental or behavioral health care provider, can get you or your child the diagnostic and treatment services needed to get better.

How do I use preventive care services?

Schedule an appointment for any check-ups, screenings or other preventive care through your or your child's Medi-Cal Managed Health Care Plan (MCP) or talk to your or your child's doctor or other health care provider. Nothing is more important than your health or the health of your child, so don't delay. Call today to schedule an appointment.

Who can I call if I have questions?

- **Medi-Cal Member Help Line**
Medi-Cal Fee-for-Service (also called regular Medi-Cal) beneficiaries can call 1-800-541-5555 (TDD 1-800-430-7077) or visit: <http://dhcs.ca.gov/mymedi-cal>
- Contact **Member Services** at your or your child's MCP for general questions.
- **Child Health and Disability Prevention (CHDP)**
Contact your county CHDP Program or your MCP
County listing: <https://www.dhcs.ca.gov/services/chdp/Pages/CountyOffices.aspx>
- **Specialty Mental Health**
Call 1-888-452-8609 or contact your county Mental Health Plan (MHP)
- **Substance Use Disorder**
Call 1-800-879-2772 24 hours a day, 7 days a week.
- **Denti-Cal**
Call 1-8002-322-6384 (TTY 1-800-735-2922) Monday through Friday 8:00 a.m. to 5:00 p.m.

If you have general questions about Medi-Cal, The Department of Health Care Services (DHCS) Ombudsman Office helps people with Medi-Cal understand their rights and responsibilities. You can call the **Ombudsman Office** at 1-888-452-8609 Monday through Friday 8:00 a.m. to 5:00 p.m. This call is free.

Final FY 2019-20 Budget: Mental Health

- **Established the Family Urgent Response System (FURS):** \$15 million in 2019-20 and \$30 million ongoing for FURS, a 24/7 statewide hotline and county mobile response system that will help ensure foster youth and caregivers can access trauma-informed supports during critical moments.
- **Mental health youth drop-in centers:** Through the Mental Health Services Oversight and Accountability Commission, \$15 million from Mental Health Services Fund one-time for establishing local centers to provide integrated youth mental health services.
- **Mental health services for students:** \$50 million in Proposition 63 funding (\$10 million of this is ongoing) to provide competitive grants to partnerships between county mental or behavioral health departments and school districts, charter schools, and county offices of education; and a mix of funding to provide mental health services for higher education students at community colleges, California State University, and the University of California.
- **Mental health workforce:** Approves \$60 million (Prop. 63 and General Fund) to fund the five-year Workforce Education and Training (WET) plan to train mental health professionals, as well as \$2 million one-time to fund pediatric residencies.

- **Developmental screenings:** AB 1004 (McCarty) would require reporting of Medi-Cal developmental screenings and establish value based incentives for screenings. *Status: Signed*
- **Improving Medi-Cal Access:** AB 1642 (Wood) addresses adjustments to foundational processes and standards within Medi-Cal, including network adequacy monitoring, rate setting considerations, penalties for low performance. *Status: Signed*
- **Youth Mental Health:** SB 428 (Pan and Portantino) would require a percentage of staff at schools to be trained in youth mental health first aid. This training equips school staff with the vital skills needed to support adolescents suffering from mental health or substance use issues, which includes knowing how to safely de-escalate crisis situations. *Status: Governor's Desk*
- **Maternal Health:** SB 464 (Mitchell), the California Dignity in Pregnancy and Childbirth Act, would require hospitals and alternative birth centers or primary care clinics that provide perinatal care to implement an implicit bias program for all health care providers involved in perinatal care of patients. *Status: Governor's Desk*

**Suggestion for Parent Leaders:
Get Involved in Health Plan
Community Advisory Committees**

For more information, visit

www.childrennow.org

**To join The Children's
Movement, visit**

www.childrennow.org/thechildrensmovement/



Follow us on Social Media

Medi-Cal Beneficiary Notice

Parent Perspective and Input

[Date]

Important Information About Preventive Care Services Through Medi-Cal

Dear Medi-Cal Beneficiary,

Please read this letter for important information about your or your child's health care.

You are getting this letter because you or your child can get preventive care services such as Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services through Medi-Cal.

Who is eligible for preventive care services?

Infants, children, and youth up to age 21 with full-scope Medi-Cal are able to get preventive care and screening services at no cost.

What are preventive care services?

These services are available to make sure that infants, children and youth under age 21 get age appropriate preventive care, like screenings for medical, dental, vision, hearing, mental health, and substance use disorders. You or your child can also get developmental services, specialty care and vaccinations to keep you healthy. Medi-Cal covers screening services (including lead blood level assessment) any time there is a need for them, even if it is not during your regular check-up. All preventive care and screening services are at no cost to you.

Check-ups and screenings are important to help the health care provider find problems early. When a problem is found during a check-up or screening, Medi-Cal covers the care needed to fix or help any physical or mental health problem. The doctor, dentist, other health care provider, county Child Health and Disability Prevention program (CHDP), or county mental or behavioral health care provider, can get you or your child the diagnostic and treatment services needed to get better.

How do I use preventive care services?

Schedule an appointment for any check-ups, screenings or other preventive care through your or your child's Medi-Cal Managed Health Care Plan (MCP) or talk to your or your child's doctor or other health care provider. Nothing is more important than your health or the health of your child, so don't delay. Call today to schedule an appointment.

Who can I call if I have questions?

- **Medi-Cal Member Help Line**
Medi-Cal Fee-for-Service (also called regular Medi-Cal) beneficiaries can call 1-800-541-5555 (TDD 1-800-430-7077) or visit: <http://dhcs.ca.gov/mymedi-cal>
- Contact **Member Services** at your or your child's **MCP** for general questions.
- **Child Health and Disability Prevention (CHDP)**
Contact your county CHDP Program or your MCP
County listing: <https://www.dhcs.ca.gov/services/chdp/Pages/CountyOffices.aspx>
- **Specialty Mental Health**
Call 1-888-452-8609 or contact your county Mental Health Plan (MHP)
- **Substance Use Disorder**
Call 1-800-879-2772 24 hours a day, 7 days a week.
- **Denti-Cal**
Call 1-8002-322-6384 (TTY 1-800-735-2922) Monday through Friday 8:00 a.m. to 5:00 p.m.

If you have general questions about Medi-Cal, The Department of Health Care Services (DHCS) Ombudsman Office helps people with Medi-Cal understand their rights and responsibilities. You can call the **Ombudsman Office** at 1-888-452-8609 Monday through Friday 8:00 a.m. to 5:00 p.m. This call is free.

Your GOALS shape your story

- **Identify your goals. Ask:**

- What is your purpose?
- What outcome would you like?

- **Then ask:**

- What are your points?
 - What examples will you use?
 - What solutions will you offer?
-

Basic Tips

- Be simple, clear, and concise.
 - If there is a specific time allotted –
STICK TO IT!
 - Highlight your story with accessories.
 - Speak respectfully.
 - Do not point fingers.
-

Title V Needs Assessment

Overview & Next Steps

What is FHOP?



- **F**amily **H**ealth **O**utcomes **P**roject, a research group from the University of California, San Francisco (UCSF)
- The Department of Health Care Services (DHCS) contracted FHOP to conduct the “Title V Needs Assessment” of California Children’s Services (CCS), and other programs that affect children and youth with special health care needs.

What is Title V?



- Title V (5) grants are federal block grants that fund state programs
 - **Block grant:** a grant from central government which a local authority can allocate to a wide range of services
 - Title V funds support programs for children with special health needs to facilitate the development of family-centered, community-based, coordinated systems of care.
 - An effort to address community capacity to deliver services that help ensure the success of Medicaid (Medi-Cal) programs
 - Transportation, care coordination, home visiting, nutritional counseling, etc.

What is the Needs Assessment?

The Title V Needs Assessment is done every 5 years to determine how the Title V program is working for children using CCS and other systems that serve CYSHCN

■ Interviews

- Specialty care centers
- Medi-Cal Managed Care Health Plans
- County CCS programs
- Family advocacy organizations
- Children's hospitals

■ Focus Groups

- Families of children and youth with special health care needs
- Providers of care
- CCS Staff
- Medi-Cal Managed Care Health Plans

■ Surveys

- Family Surveys (over 4,500 responses)
- Provider Surveys (254 responses)
- CCS Staff Surveys (44 responses)

■ Stakeholder Group

- Family Members, Providers, CCS staff participants
- Interview Guide Workgroup, Focus Group Workgroup, Survey Workgroup

Webinar summaries of results available at fhop.ucsf.edu

Family Survey Results

What's Left?

- Issues and problems that arose from this Needs Assessment will be prioritized by stakeholder
- Webinar meetings to develop “Action Plans” for the next five years to address priorities
- The Action Plans will be part of the written Title V Needs Assessment Report that DHCS and the California Department of Public Health will submit to Human Resources and Services Administration and post on FHOP's website
- Join an Action Plan Workgroup to help develop the action plans to address prioritized needs!

Interested? Contact Ali!
abarclay@familyvoicesofca.org | 415-282-7494 ext. 136

Why is Family Engagement Important to the Needs Assessment?

Contacting FHOP:

- Please email us at: **fhop@ucsf.edu**
- Or call us at (415) 476-5283
- And Visit our website here or at the QR code below: **<https://fhop.ucsf.edu/>**



Lunch

Disparities in Access to Regional Center Services



Brian Capra

Senior Staff Attorney, Children's Rights Project
Public Counsel

Los Angeles County

East LA Regional Center

2nd Tuesday of the month, 6pm | Regional Center Boardroom, 1000 S. Fremont, Alhambra,

Lanterman Regional Center

4th Wednesday of the month, 6pm | Lanterman Regional Center, 3303 Wilshire Blvd, LA

South Central Los Angeles Regional Center

4th Tuesday of the month, 7pm | South Central LA Regional Center
2500 S. Western Avenue, LA

Westside Regional Center

2nd Wednesday of the month, 6pm | Coastal Developmental Services Foundation
5901 Green Valley Circle, Suite 320, Culver City

North Los Angeles County

San Fernando Valley Meetings

October 23, 2019; November 20, 2019; January 15, 2020; March 11, 2020; 6:30 p.m.
NLACRC, 1st Floor Conference Room, 9200 Oakdale Ave., Chatsworth

Santa Clarita Valley Meetings

Meeting date: 2/12/2020, 6:30 p.m.
NLACRC Santa Clarita Valley Office, 25360 Magic Mountain Parkway, Suite 150
Santa Clarita

Orange County

November 7, 2019; January 9, 2020; March 5, 2020; 6:00pm | Regional Center of Orange County, 1525 North Tustin Avenue, Santa Ana, 92705

Riverside County, San Bernardino County

2nd Monday of every odd month, 5pm | Inland Regional Center, 1365 South Waterman Avenue, San Bernardino, 92408

San Diego County

2nd Tuesday of the month, 12pm | San Diego Regional Center Headquarters Board Room, 4355 Ruffin Road, San Diego, 92123

San Luis Obispo County, Santa Barbara County, Ventura County

Tri-Counties Regional Center, www.tri-counties.org | (805) 962-7881

Find your Regional Center: arcanet.org

Community and Family Engagement Council



Kimberly Cooper

Communications Manager, Children's Health Outreach Initiatives

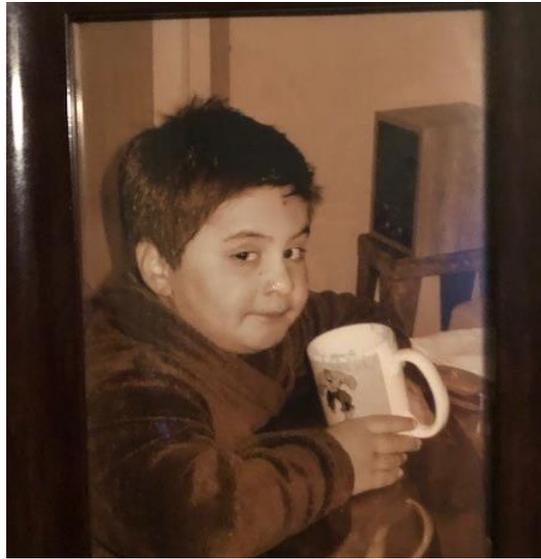
Division of Maternal, Child, and Adolescent Health

Los Angeles County Department of Public Health

Gloria Ruiz

As you can see, I spend waaay too much time with sleep deprived women triaging events and situations on shoestring budgets... The best news is, I GET to do this sort of thing with the BEST people!





Occasionally, you can find Team Ruiz hanging out...
Pete, Glo, PJ, Jack... Oh, don't forget autism and ID.
They don't forget us...

- Project Leadership has put me in places where lots of opportunity lives and breathes
 - I happen to enjoy talking to legislators
 - Securing legislative support takes time
- Building rapport with legislators requires the ability to remember, and more importantly, to forget
 - Project Leadership gives parents like me the Confidence and Roadmap to make an impact

Project Leadership in Action

As chair of our SELPA Community Advisory Committee, it made sense to develop a relationship with our local legislators. That idea paid off... California SELPAs were promised significant amount of additional funding, and pre-school/early childhood education is now promised to receive funding.



We Can Change the World! The Galaxy!

Project Leadership
graduates provide a
constant source of
support to each other.
Our network is strong.
Now go have some fun!



Alison Beier

*Special Needs Advocate
FVCA Project Leadership Alumna*



Evan
&
Teagan



- ❖ FVCA Annual Health Summit & Legislative Day
- ❖ Advocacy in DC
- ❖ Written Articles
- ❖ Public Speaking Opportunities within UCLA Health System
- ❖ Relationships With State Legislators and Their Staff
- ❖ Advisory Panel Participation
- ❖ Continued Educational Opportunities

Project Leadership in Action

Autism Society of Los Angeles
Parent Empowerment Project



- **Reducing Disparities**
- **Self-Determination**
 - *Person-Centered Planner*
 - *Independent Facilitator*

Special Needs Advocate

Project Leadership Makes a Difference

Contact: alison@autismmla.us



Kristie Sepulveda-Burchit



Educate.Advocate.
educateadvocateca.com



Empower Family
CALIFORNIA

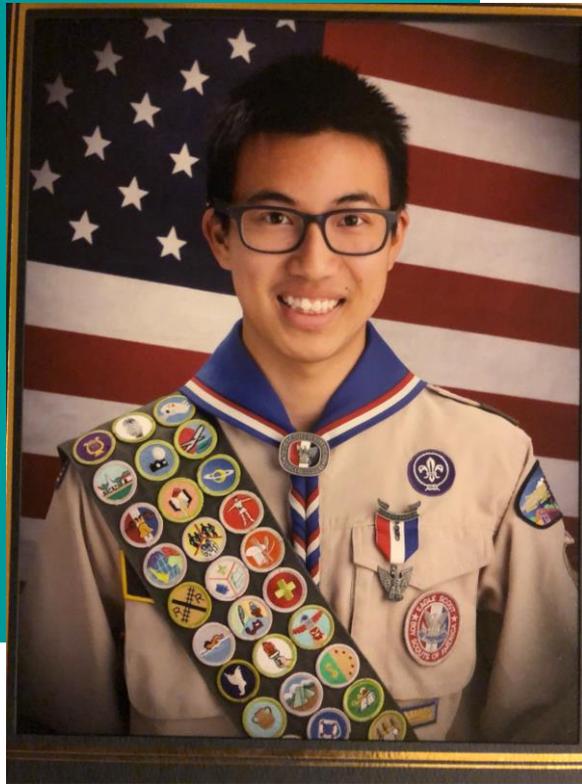
-
- Legislation advocacy began in 2011
 - Consistently supporting legislation in 2017, 2018, 2019
 - Brought a bill package to legislator offices in both 2018 and 2019
 - Bill picked up in 2018 but did not go forward because of the DDS rate study
 - Two bills picked up in 2019 one proceeded forward AB 605

AB 605 Special education: assistive technology devices

Next Steps

- Always looking for good bill ideas and people who want to help with them!
- Will bring a bill package in for 2020
- Will continue fostering relationships with legislators and staffers
- Look to partner with organizations to support legislation that positively impacts our families
- Would love to connect with those who want to help!
- Educate. Advocate.
educateadvocateca@educateadvocateca.com

Leck Lee



Chris Lin
Leck Lee
Yulan Lin
Yumei Lin
YushenLin
Hong Lin
Lillian Lin



- ❑ **Vice President:**
CPAD-Chinese
Parents for the
Disabled
- ❑ **Board member:**
Institutional Review
Board of Easter Seal
Autism Service

- ❑ I learn to present my
cause in a more focus
and effective manner
- ❑ I learn the ins and outs
of our state
government and how
to advocate for our
cause through the help
of the legislatures

Results



U.S. Representative Judy Chu

Closing Remarks

Evaluation, Stipend Forms, Group Photo