

Thanks to Our Sponsors

FAMILY VOICES of California

17th Annual Health Summit
March 11, 2019

LEADERSHIP



SPIRIT



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COLLABORATION



HOPE



FAMILY VOICES OF CALIFORNIA
2019 HEALTH SUMMIT & LEGISLATIVE DAY
Advocacy & Leadership Strategies
March 10, 2019



HEALTH SUMMIT & LEGISLATIVE DAY

- ❑ Day 1: Advocacy & Leadership Skills for Families
- ❑ Day 2: Health Summit
- ❑ Day 3: Legislative Day



HEALTH SUMMIT & LEGISLATIVE DAY: EXPECTATIONS

- ❑ High quality tools and skills for effective advocacy
- ❑ Information about key issues affecting children and youth with special health care needs (CYSHCN) and disabilities
- ❑ Opportunities to build a network
- ❑ Active and sustained engagement with decision makers

ADVOCACY AND LEADERSHIP STRATEGIES FOR FAMILIES: OBJECTIVES

- ❑ Move from individual to systems advocacy
- ❑ Review key policy issues and discussion points
- ❑ Boost advocacy tools and proficiency
- ❑ Create an impactful 1-2 minute story
- ❑ Prepare for legislative visits

SHARE YOUR EXPERTISE & EXPERIENCES

Seeking parents for “virtual” hospital advisory board

VIRTUAL hospital advisory board

Submit your completed card to any Family Voices of California staffer

- ☐ Had multiple and/or lengthy hospital stays?
- ☐ Have advisory board experience?
- ☐ Ready to move to *systems* advocacy?
- ☐ Interested in health care quality improvement?
- ☐ Available for regular & periodic calls?

Name:

Email:

Phone:

Age of child/loved one:

County of residence:

Most frequent hospital:



INTERESTED?

Completion of this form does not enroll or commit you to serve. It is only to express interest. familyvoicesofca.org



PARENTS INFORM

FAMILY VOICES OF CALIFORNIA: A STATEWIDE COLLABORATIVE

*Working to
ensure quality
health care for
children and
youth with
special health
needs*

Expand the capacity of parent centers to provide health care information

Build partnerships between families, decision makers and professionals

Provide information and a forum for families to advocate for health systems improvements

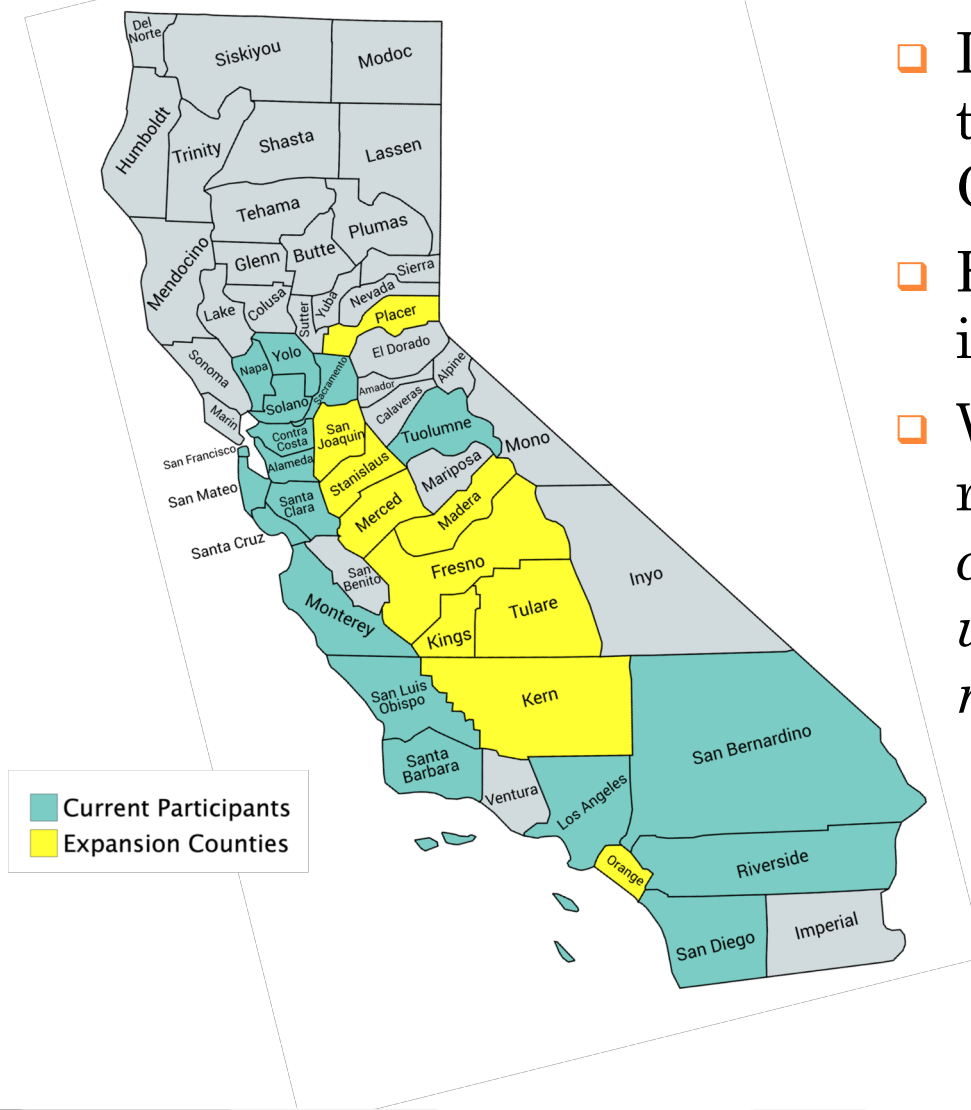
A Child with Special Health Care Needs (CSHCN) is defined as having:

One or more chronic physical, developmental, behavioral, or emotional condition(s) that require health and support services beyond that required by children generally

-Health Resources and Services Administration Maternal and Child Health-

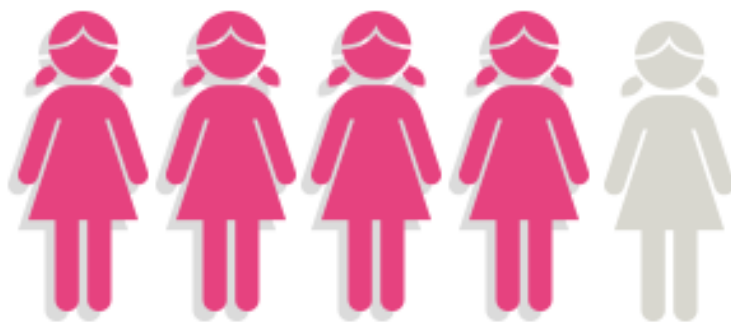


PROJECT LEADERSHIP IN CALIFORNIA



- ❑ Increasing the ability of parents to advocate for the needs of CYSHCN
- ❑ Helping families move from individual to systems advocacy
- ❑ Working toward family representation at *all levels of community and government where health care decision making occurs*





Four out of Five



Children with special health care needs in California do not receive care that meets federal minimum quality standards

CA RANKS LAST

When it comes to families' shared decision-making with health care providers

HALF

Do not receive effective care coordination

40%

Have a hard time obtaining community based services, such as finding doctors and scheduling appointments

46th

California state ranking on care coordination

Children with Special Health Care Needs (CSHCN): A Profile of Key Issues in California, Child and Adolescent Health Measurement Initiative, Lucile Packard Foundation for Children's Health, January 2013 accessed 4.14.15 at http://cshcn.wpengine.netdnacdn.com/wp-content/uploads/2013/01/Christy-report_01-22-13.pdf

ADVOCACY

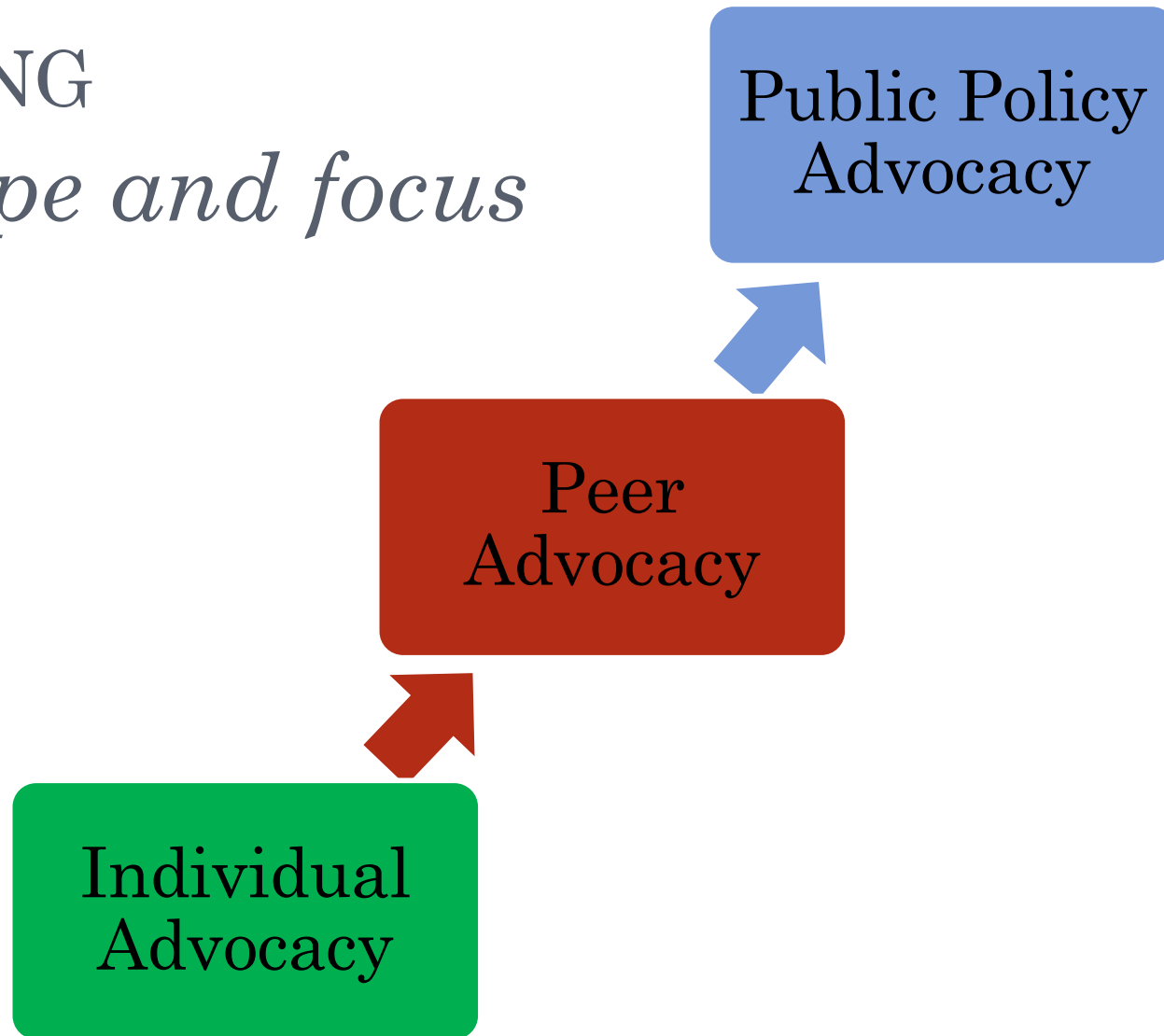
Speaking

Writing

Acting

in support of a cause

CHANGING *your scope and focus*

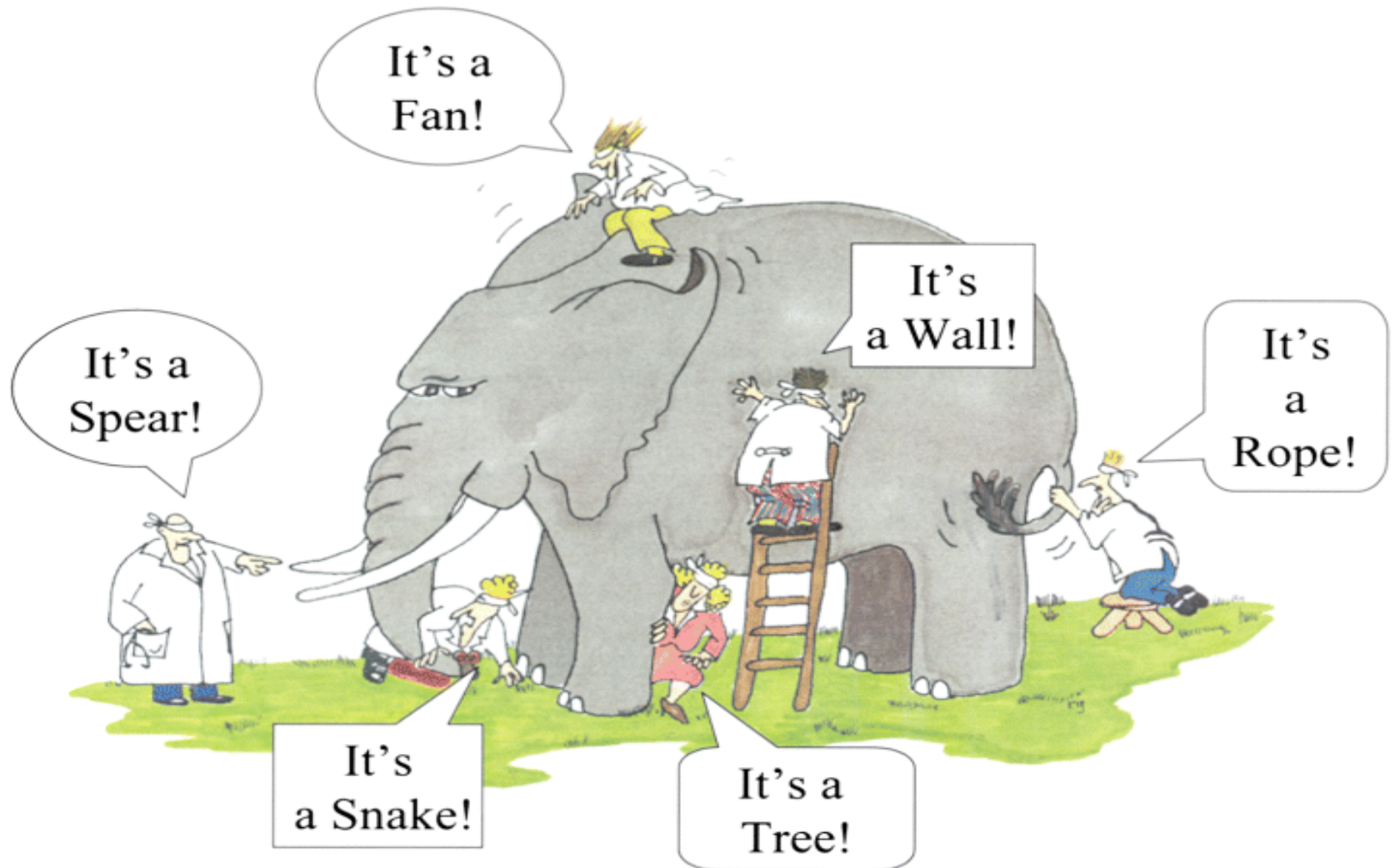


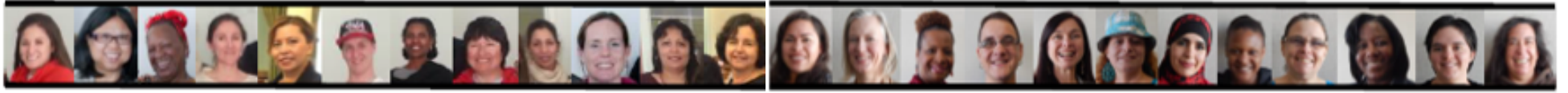
real
life.

PARENTS MAKE EXCEPTIONAL ADVOCATES

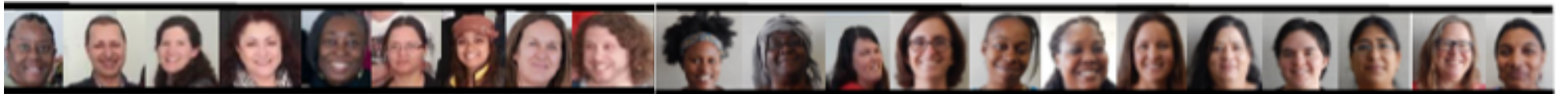
- ❑ Families have unique and authentic experiences to share.
- ❑ As consumers, families are in an ideal position to honestly evaluate *the impact* of policies.
- ❑ Families are problem solvers.

PERSPECTIVE IMPACTS EVERYTHING

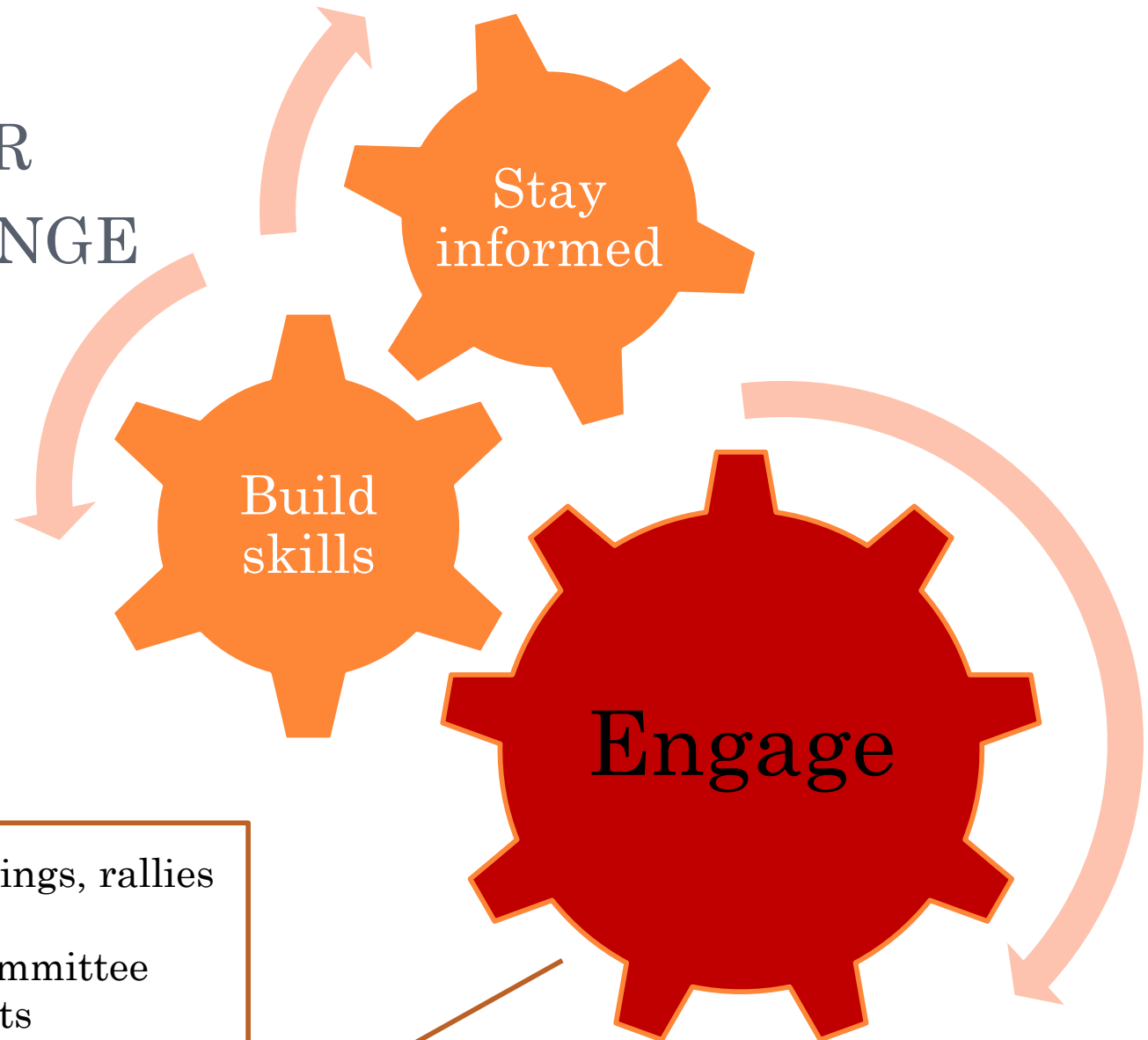




Our stories help shape
perceptions by
bringing a powerful
reality



WAYS TO ADVOCATE FOR SYSTEMS CHANGE



- Attend hearings, meetings, rallies
- Give public comment
- Serve on a board or committee
- Respond to action alerts
- Use social media *effectively*
- Meet with elected officials & staff

BRANCHES OF GOVERNMENT

Legislative



Makes laws & oversees financing

- Federal: Senate & House of Representatives
- State: Senate & Assembly

Executive



Carries out Laws

- Federal: President, Departments, Agencies
- State: Governor, Departments, Agencies

Judiciary



Interprets Laws

- Federal: Courts
- State: Courts



STATE LEGISLATIVE BRANCH



- ❑ **STATE SENATE** (40 Members) – 4 year terms
- ❑ **STATE ASSEMBLY** (80 Members) – 2 year terms
- ❑ Districts are based on population
- ❑ Those elected after 2012 can serve up to 12 years



STATE EXECUTIVE BRANCH

GOVERNOR:

- ❑ Signs or vetoes proposed laws passed by legislature
- ❑ Appoints judges
- ❑ Proposes state budget and other new laws
- ❑ Commands state militia
- ❑ Grants pardons
- ❑ Oversees state agencies, departments, boards, and commissions

STATE AGENCIES AND DEPARTMENTS

- ❑ More than 500 state agencies, departments, and commissions
- ❑ Departments report directly to agencies
- ❑ Agencies report directly to governor
- ❑ Implement laws, including writing and enforcing regulations



Anyone can suggest an idea for a bill

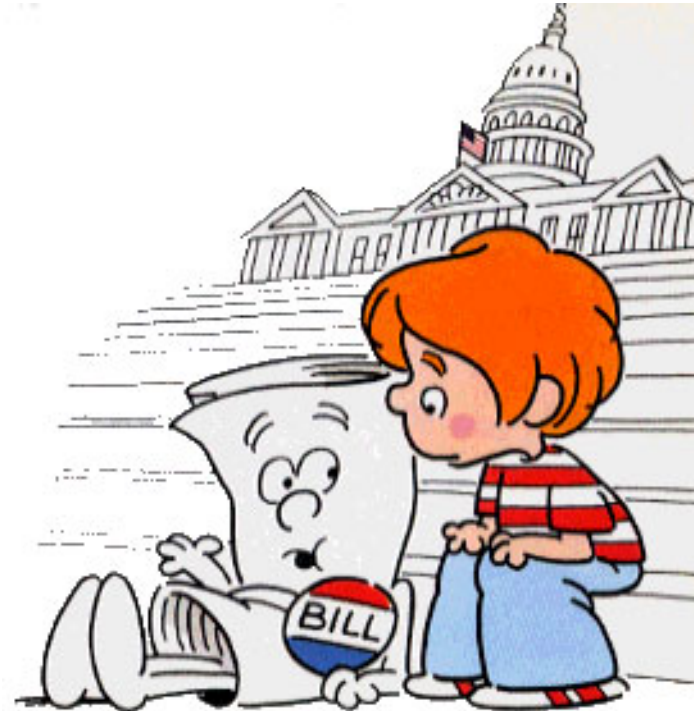
- Governor or other constitutional office
- Lobbyists or special interest groups
- Legislators and staff
- Media sources
- Community members and organizations
- Citizens

How a bill becomes law



*Most bills become law on January 1 of the following year.

HOW A BILL BECOMES A LAW



<https://www.youtube.com/watch?v=FFroMQlKiag>

TRACKING LEGISLATION

- ❑ Get bill summaries, histories, status, analyses
- ❑ Monitor progress
- ❑ Sign up for alerts

Look up by bill number,
author, topic:

<http://leginfo.legislature.ca.gov>

The screenshot shows the California Legislative Information website. At the top, there is a navigation bar with links: skip to content, home, accessibility, FAQ, and feedback. Below this is a header with the California state seal and the text "California LEGISLATIVE INFORMATION". A tabbed menu below the header includes: Bill Information, California Law, Publications, Other Resources, My Subscriptions, and My Favorites. The main content area is divided into three columns. The left column, titled "TODAY'S SCHEDULE" with the date "Fri, Mar 8, 2019", is currently empty. The middle column, titled "WELCOME", contains a welcome message and a "Quick Bill Search" section with input fields for "Bill Number" and "Keywords(s)", and a "Go" button. The right column contains a "Quick Code Search" section with a "Code" dropdown menu, "Code Section", and "Keywords(s)" input fields, and a "Go" button. To the right of the "Quick Code Search" section is a "Daily Updates" section with links for "Assembly Updates", "Senate Updates", and "Daily Files". Below these are "Quick Links" including "Senate Video Archive", "Assembly Video Archive", "Downloadable Database", "CA Agency Reports", and "Register to Vote".

THE BUDGET PROCESS



- ❑ Why is the budget important to you?
- ❑ Why is it an important policy-making tool?
- ❑ What is the budget process?



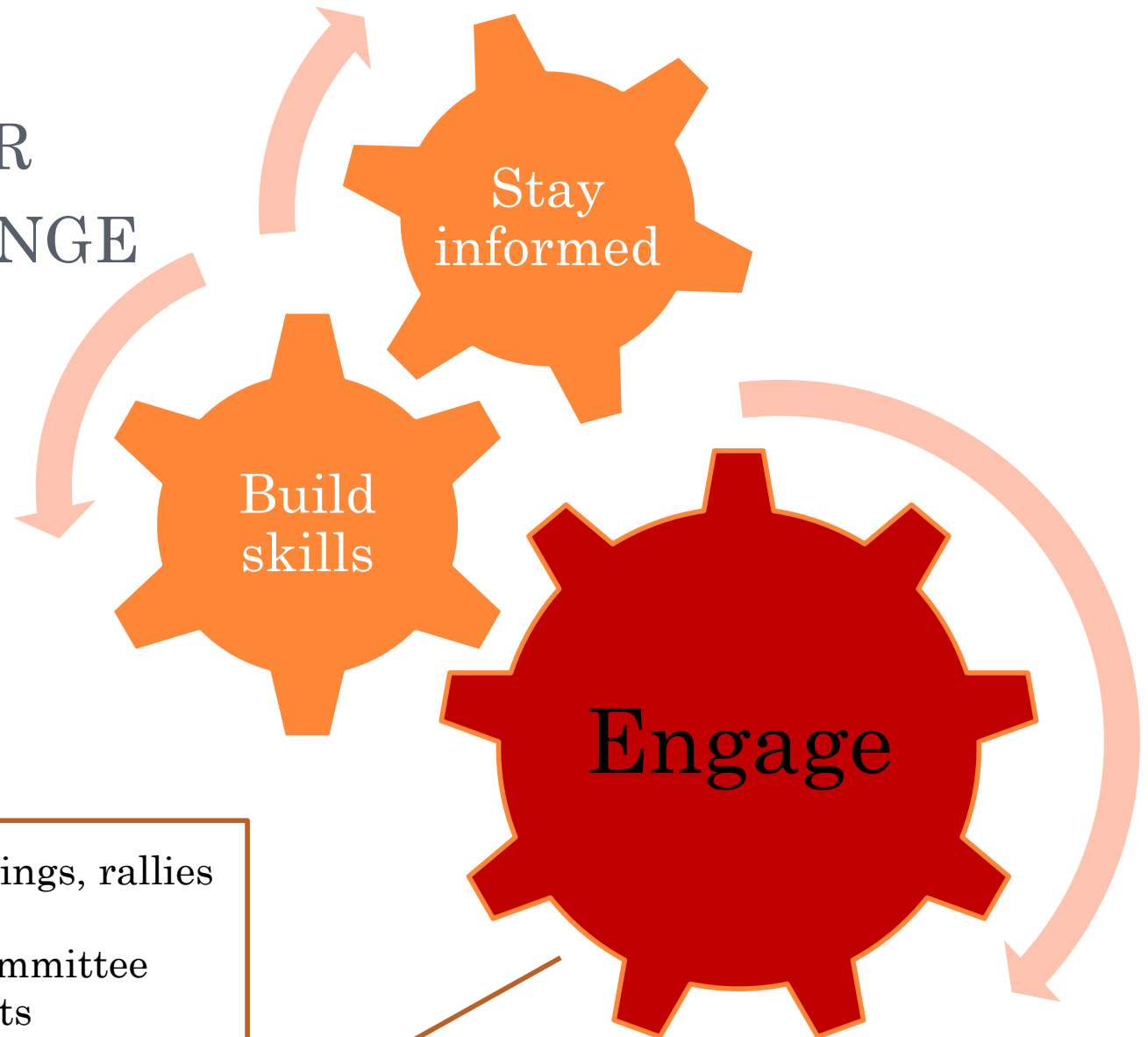
STATE BUDGET DEADLINES



- ❑ **January 10** – Presented & introduced
- ❑ **May 10** – Revised & analyzed
- ❑ **June 15** – Constitutional deadline to pass the budget

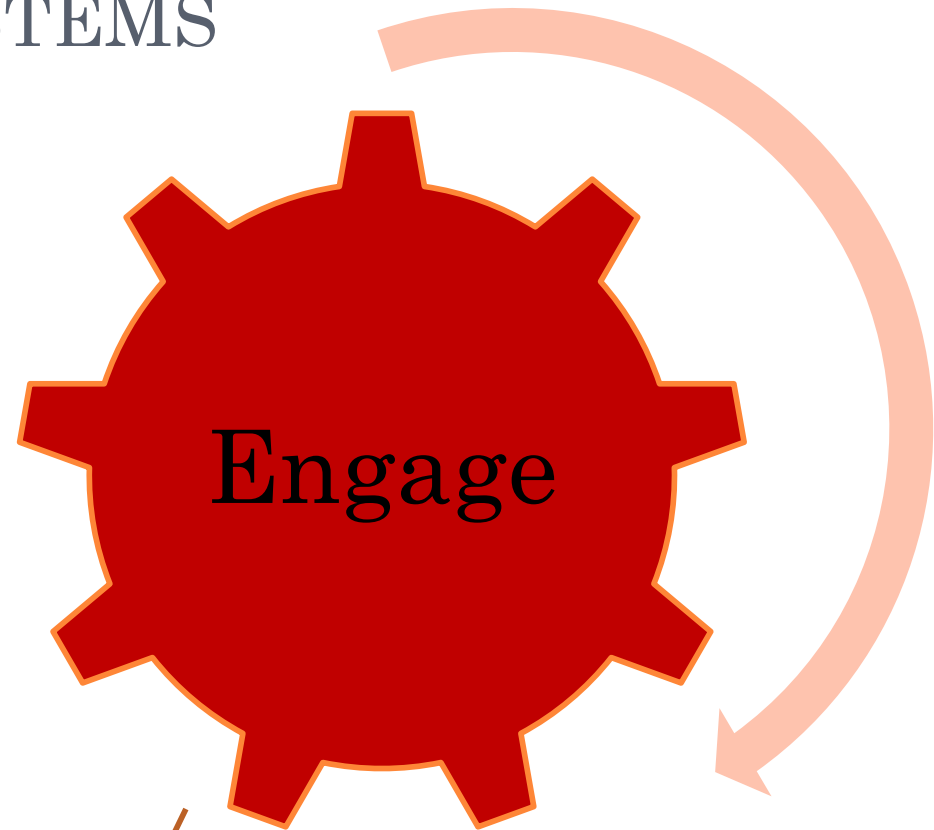
Because the budget contains both appropriations and an urgency clause, it must be approved by a **2/3 vote** in each house.

WAYS TO ADVOCATE FOR SYSTEMS CHANGE



- Attend hearings, meetings, rallies
- Give public comment
- Serve on a board or committee
- Respond to action alerts
- Use social media *effectively*
- Meet with elected officials & staff

FOCUS: HEALTH SYSTEMS IMPROVEMENT



- Stay informed
- Attend hearings, meetings, rallies
- Give public comment
- Respond to action alerts
- Use social media *effectively*
- Meet with elected officials & staff

GETTING TO KNOW YOUR ELECTED OFFICIALS

- ❑ Who are your elected officials?
- ❑ What is their background and reputation?
- ❑ Do they care about your issues?
- ❑ What do they care about?
- ❑ How can they impact health policy affecting CYSHCN?
- ❑ How can you connect?

Find your legislator:

<http://findyourrep.legislature.ca.gov/>



STORIES EDUCATE, INFORM & CONNECT

- ❑ Demonstrate that disabilities / chronic medical conditions are part of the human experience.
- ❑ Dispel myths about disabilities / chronic medical conditions.
- ❑ Give an understanding of what it is like to live with a disability / chronic medical condition.



IMPACTFUL STORIES CREATE CHANGE BY:



<http://www.youtube.com/watch?v=JU1shpujZ6g>

- ❑ Making abstract ideas real, personal, and concrete.
- ❑ Increasing understanding of life with a CYSHCN.
- ❑ Providing a connection between people.
- ❑ Demonstrating larger social successes and failures.

CRAFTING A STORY FOR IMPACT

- ❑ Identify a goal or “ask”
- ❑ Know your audience
- ❑ Share knowledge and passion
- ❑ Provide context and *relevant* details
- ❑ Present a conflict, challenge, or positive outcome
- ❑ Paint a picture
- ❑ Make it short and to the point (1-2 min max)



BASIC TIPS

- ❑ Be simple, clear, and concise.
- ❑ Paint a picture with specific examples.
- ❑ Stick to the allotted time.
- ❑ Highlight your story with accessories.
- ❑ Do not talk about others without their permission.
- ❑ Speak respectfully.
- ❑ Do not point fingers.
- ❑ Make your "ask."

THE OUTLINE

Basic 8 for Developing Your Story	My Story
1. What is the purpose for my presentation?	ASK for support for I/DD Funding increase
2. What outcome would I like from my audience?	To be a co-author of legislation
3. What powerful examples do I have that I am willing to share?	my child had to wait 9 mos. for an ABA provider. His safety was compromised. We couldn't go out as a family
4. How do I organize my points with my examples?	We tried to go to the supermarket but he had a meltdown and broke glass shelves, cutting himself.
5. What visual aide, creative wording, or reading, or "audience hooks" will I use?	picture before therapy & now brothers drawing "scared" of my brother.
6. What solutions or suggestions will I give my audience?	Please support the proposal to increase funding for I/DD so my son's services can be provided and he can stay safe.
7. How will I close?	Will you support this proposal? Would you consider signing a letter of support or co-authoring the bill?
8. What will I do if I get nervous and don't know what to say next?	use my bullet points

2019 KEY ISSUES

1. Timely access to care, treatment, and services.
 - Incentives for students to fill the shortage of psychiatrists (AB 565, Maienschein)*
2. High quality community based services, providers, and programs.
 - Budget proposal for an 8% across the board increase in funding for the I/DD system

**This is just for demonstration purposes. FVCA does not take a position on any bill.*

5.5. TELLING YOUR OWN STORY

Basic 8 for Developing Your Story	My Story
1. What is the purpose for my presentation?	
2. What outcome would I like from my audience?	
3. What powerful examples do I have that I am willing to share?	
4. How do I organize my points with my examples?	
5. What visual aide, creative wording, or reading, or "audience hooks" will I use?	
6. What solutions or suggestions will I give my audience?	
7. How will I close?	
8. What will I do if I get nervous and don't know what to say next?	

The em**POWER**ment of legislative visits



PREPARING FOR LEGISLATIVE MEETINGS

- ❑ Make an appointment
- ❑ Identify your “team”
 - Main point person to lead & facilitate
 - Define the objectives of the visit
 - Everyone contributes during the meeting
 - At least one constituent
 - Different but related stories
- ❑ Confirm everything a few days ahead
 - Time, location, who’s in the meeting
- ❑ Think of factors to anticipate

DURING THE VISIT

1. Set the climate
2. Team leader introduces & states reasons for the visit
3. Each person shares as time permits
4. Always make an ask – what do you want?
5. Ask them if they can support your request
6. Provide materials to support your stories & requests
7. Get business cards and take a picture!

Things to Remember

- ❑ If you don't know, say so. Offer to find out and get back to them.
- ❑ Be alert to other matters and time constraints
- ❑ Keep it simple and avoid technical lingo and acronyms.





AFTER THE MEETING

- ❑ Hold a debriefing.
- ❑ Send a follow-up email with a photo
- ❑ Post/tweet your photo and tag the legislator
- ❑ Monitor any bill/proposal and their action
- ❑ Follow up
- ❑ Tell us about your meeting!



TEAM PLANNING

- ❑ Identify your team leader
- ❑ Map out your visits
- ❑ Begin with an Intro Statement

We are _____
Advocating for _____
To ensure _____

Sample:

We are parents advocating for our children with special health care needs and disabilities to ensure they have full and timely access to high quality, community based treatment, care, and services.

TEAM PLANNING

Legislative Visit – Planning Worksheet

Legislator: _____

Meeting with: _____

Time: _____

Location: _____

Things to know: _____

What's important to them? _____

How can you connect? _____

Team Leader: _____

Participants: _____

Topic/Story: _____

1. _____

2. _____

3. _____

4. _____

5. _____

What is your "ask(s)?" _____

Notes: _____

CHECKLIST

- ___ Team leader
- ___ Participant roles/speaking points
- ___ Leave behind materials
- ___ Ask for business card
- ___ Make your "ask(s)"

- ___ Ask for support/ what can they do?
- ___ Take a picture
- ___ Tweet/Facebook picture, tag legislator
- ___ Send follow up email with picture, leave behind
- ___ Other

THANK YOU!

- ❑ Evaluations
- ❑ Hospital Advisory Board interest cards
- ❑ Continental Breakfast and Registration tomorrow 7:30am-8:30am

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