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

☐ 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?

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

INTERESTED?

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

**Four out of Five**

ADVOCACY

Speaking
Writing
Acting

in support of a cause
CHANGING your scope and focus

Public Policy Advocacy

Peer Advocacy

Individual Advocacy
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

It’s a Fan!

It’s a Wall!

It’s a Rope!

It’s a Spear!

It’s a Snake!

It’s a Tree!
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

Stay informed
Build skills
Engage
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

*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 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

Engage

Stay informed

Build skills

- 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:

- 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.

http://www.youtube.com/watch?v=JU1shpujZ6g
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."
<table>
<thead>
<tr>
<th>Basic 8 for Developing Your Story</th>
<th>My Story</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is the purpose for my presentation?</td>
<td>Ask for support for IPD Funding increase</td>
</tr>
<tr>
<td>2. What outcome would I like from my audience?</td>
<td>To be a co-author of legislation</td>
</tr>
<tr>
<td>3. What powerful examples do I have that I am willing to share?</td>
<td>My child had to wait 9 mos. for an ABA provider. His safety was compromised. We couldn’t go out as a family. We tried to go to the supermarket but he had a melt-down and broke glass shelves, cutting himself.</td>
</tr>
<tr>
<td>4. How do I organize my points with my examples?</td>
<td>We tried to go to the supermarket but he had a melt-down and broke glass shelves, cutting himself.</td>
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<tr>
<td>5. What visual aide, creative wording, or reading, or “audience hooks” will I use?</td>
<td>A picture before therapy of my brother’s “scared” of my brother.</td>
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<td>6. What solutions or suggestions will I give my audience?</td>
<td>Please support the proposal to increase funding for IPD so. my son’s services can be provided and he can stay safe.</td>
</tr>
<tr>
<td>7. How will I close?</td>
<td>Will you support this proposal? Would you consider signing a letter of support or co-authoring the bill?</td>
</tr>
<tr>
<td>8. What will I do if I get nervous and don’t know what to say next?</td>
<td>Use my bullet points</td>
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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

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

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**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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