Background of Project Leadership:
Family Voices of California’s (FVCA) Project Leadership is designed to help family members develop the skills and tools they need to partner at all levels of decision making and engage in public policy advocacy activities on behalf of children and youth with special health care needs (CYSHCN). To date, nearly 90 facilitators from more than 60 organizations have trained 280+ family members. Project Leadership includes:

- A 2-day Training of Trainers workshop.
- A seven-session parent/family training program, available in English, Spanish, and Chinese.
- Linkages to local and statewide committees, task forces, and opportunities for input.
- Ongoing assistance and mentorship for program graduates, including membership to an online Project Leadership Advocacy community.
- Opportunities to participate in FVCA health policy forums.

The Lucile Packard Foundation for Children’s Health funds Project Leadership. Learn more:

The Project Leadership Training of Trainers
FVCA conducts Training-of-Trainees workshops for representatives of agencies/organizations serving or representing families of children with special health needs and/or disabilities. The 2-day workshop prepares participants to implement the Project Leadership training and mentorship in their communities. Participants learn best practices for implementation, and review content and activities. 2019 workshops will be in Stockton, Orange County, and Bakersfield, California. 2020 workshops will be in two U.S. regions, TBD.

Training of Trainer Selection Process:
Participants are selected through an application or nomination process based on level of interest and capacity to further Project Leadership goals and objectives. Participants must attend the full 2-day workshop.

Expectations of Agencies/Organizations and Trainers
☐ Commit to implement Project Leadership locally: Recruit and begin training family members of children with special health care needs within 12 months of completing a Training-of-Trainers workshop.
☐ Be responsible for obtaining funding for local training series.
☐ Participate in the Project Leadership online Advocacy Community (i.e., private Facebook page).
☐ Participate in 1-2 calls annually.
☐ Share information and opportunities from FVCA with graduates.
☐ Link Project Leadership graduates to the FVCA network, including a graduate database, the Project Leadership online Advocacy Community, alumni gatherings, and future conferences.
☐ Collect and provide FVCA with training dates, training language, graduate names, and contact information (phone, email address), at the end of each training series.

➢ Family Voices of California considers participants to be “Project Leadership Graduates” if they have completed a minimum of 6 out of 7 (85-90%) of the training series.

Learn more
- An informational Webinar is available at familyvoicesofca.org in the Webinar archive.
- Questions? Contact Elaine Linn at elinn@familyvoicesofca.org.
PROJECT LEADERSHIP – Summary Table of Contents

Chapter 0: Pre-Training

Chapter 1: Knowing the Past to Change the Future: *History and Purpose of Advocacy*

- Key Legislation and Policies
- The Disability Rights Movement
- What Does It Mean to Advocate?
- Current Issues

Chapter 2: Rules of the Road: *Systems, Laws, and Entitlements*

- How Policies are Made
- Important Laws and Public Systems
- Making the Connection: From Individual to Public Policy Advocacy

Chapter 3: Becoming a Mover and Shaker: *Working with Decision-Makers for Change*

- Your Elected Officials
- How Bills Become Laws
- The California Budget Process
- Providing Testimony
- Building Relationships with Legislators
- Working with the Media

Chapter 4: Playing Well with Others: *Enhancing Communication*

- Enhancing Personal Communication Skills
- Effective Listening
- Partnering with Your Child

Chapter 5: Telling Your Story: *Developing and Presenting Stories to Others*

- The Importance of Storytelling
- Developing Your Story
- Presenting and Evaluating Your Story

Chapter 6: Ways You Can Serve: *Participating on Decision Making Bodies*

- The Value of Participation
- Places to Serve
- Plan for Success
- Rules for Participation

Chapter 7: Solidifying Partnerships: *Connecting with Local Change Makers*

- Connecting with Local Leaders and Advocates
- Your Action Plan: Presentations and Peer Review
- Celebrate!

Updated April 2019
Project Leadership

Engaging families to impact health policies for CYSHCN

Elaine Linn
Family Voices of California
Family Voices Family Leadership Conference 2019

Today's Objective: Develop informed tactics for shaping the next generation of policymakers through parent advocacy and leadership

Family Voices of California

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

90 Trainers 62 Organizations 280+ Graduates 5 States

Parent Leaders

- Who has inspired you to be a leader?
- When did you first realize you were a leader?
- What keeps you motivated?

Parent Leaders

Knowing the Past to Change the Future

Changing Scope and Focus

Systems Advocacy
Working to make a difference for many

Peer Advocacy
Speaking up with/for others

Individual Advocacy
Speaking up for myself, my child, my family

Project Leadership Graduates in Action

- Confident they can tell their child’s story 99%
- Confident they can participate in policy change discussions with policymakers 94%
- Frequently use the skills they gained during their training. 79%


Project Leadership Graduates in Action

- Using their skills for systems focused advocacy 90%
- Participated on a committee, board, council, stakeholder, or other group focused on children with special health care needs/disabilities 75%
- Reported a policy or systems change or improvement 40%

Nearly 2/3 of graduates contacted their legislators

54% of these have made in-person visits


An Example: California’s “System” of Care

Source: Lucile Packard Foundation for Children’s Health

Developing the Action Plan

- Know what you want
- Get the facts
- Plan the strategy
- Gather support
- Be firm and consistent
- Maintain integrity and credibility
4. HOW CONCERNED ARE YOU ABOUT THE FOLLOWING, FOR YOUR CHILD/FAMILY? (Please check just one box for each issue/service)

<table>
<thead>
<tr>
<th>Issue/Service</th>
<th>Very Concerned</th>
<th>Moderately Concerned</th>
<th>Slightly Concerned</th>
<th>Important to me but I’m not concerned</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Affordable Care Act</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Education</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment</td>
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<td></td>
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<tr>
<td>Dental</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental health</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
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</tr>
<tr>
<td>Housing</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

5. FROM THOSE LISTED ABOVE, WHAT ARE YOUR TOP 2 CONCERNS?

   A. Protect Affordable Care Act
   B. Mental Health

6. CHOOSE ONE TO FOCUS ON, FOR NOW: Mental Health

   I would like… To get better and more accessible MH care and treatment at the school site, where things are triggered.

   Why is this important for YOU? My son needed mental health support at school.

   Why did this happen? There was no one he could trust at school and repeated incidents caused his condition to worsen.

   Why did this happen? There was no one on site with training or willingness to help.

   Why was this a problem? Only school-based intervention could address immediate situations and prevent crisis, damage, and suicide for students.

   What is the first step YOU CAN TAKE to achieve this? Talk to my legislator about co-sponsoring AB 8 (Chu), and sharing my story.

Perspective Impacts Everything

Our stories help shape perceptions by bringing a powerful reality
Telling Your Story

- 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)

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

The Outline

5.5. TELLING YOUR OWN STORY

<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>Explain how having a mental health professional on a school campus can change lives.</td>
</tr>
<tr>
<td>2. What outcome would I like from my audience?</td>
<td>I would like Assemblyman Kiley to co-author AB 8 (Chu)</td>
</tr>
</tbody>
</table>
| 3. What powerful examples do I have that I am willing to share? | - Bullying and mishandling — didn’t feel safe  
  - Forced to confront bullies, shake hands, and apologize  
  - Distrust of adults on campus, lived in fear  
  - Mental, physical problems jeopardizing health |
| 4. How do I organize my points with examples? | - Introduce my son & what happened  
  - Explain how having a mental health professional at school helped him  
  - Would like Assemblyman Kiley to co-author AB 8 (Chu) |
| 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? | |
### Organizing your Story

- Introduce yourself.
- State why you are there.
- Talk about your experience/your story.
- Explain why your story is important.
- The Ask: What do you want your audience to do?
- Thank your audience.

### Next Steps

- What challenges and needs do your families face?
- What role do you have in nurturing and engaging in parent leadership?
- What are the tools, strategies and resources you may use?

### Basic 8 for Developing Your Story

<table>
<thead>
<tr>
<th>5. What visual aide, creative wording, “audience hooks” will I use?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Photo of my son on 1st day of 1st grade</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. What solutions or suggestions will I give my audience?</th>
</tr>
</thead>
<tbody>
<tr>
<td>School mental health professionals understand the unique environment and can help resolve issues when they occur, and recognize and avert crisis</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7. How will I close?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thank you</td>
</tr>
<tr>
<td>School therapist helped my son get through HS so he could go to his dream college</td>
</tr>
<tr>
<td>Please co-author, help pass AB 8 to help others</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8. What will I do if I get nervous?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use notes/bullet points</td>
</tr>
</tbody>
</table>
2020: Regional Trainings

- Two regional Training of Trainer workshops
- Regions will be based on interest
- Seeking host organizations

Engaging families for health systems change

- Want to help families move to systems advocacy?
- Ready to expand staff & organization capacity?
- Want to have greater impact with decision makers?
- Interested in attending a FREE regional training?
- Interested in hosting a Project Leadership workshop?

This does not commit you to host or attend a workshop. It is only to express interest.

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Project Leadership Grads are Saying…

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Cynthia Torres > Project Leadership Alumni
Advocacy Clinic

Today I attended my first town hall with our regional center. I gave public comment and although nervous it was able to get my thoughts organized and put within the right context. Thanks to all the skills I learned from the Project Leadership class. So grateful to be a part of this group of empowering leaders. At the end of the town hall I received an invitation from the regional center executive director to apply to be a participating member on the board of directors. Thank you #FamilyVoiceCA