

Project Leadership Training-of-Trainers

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:

www.familyvoicesofca.org and <http://www.lpfch.org/publication/project-leadership-effecting-change-one-parent-time>.

The Project Leadership Training of Trainers

FVCA conducts Training-of-Trainers 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!

Project Leadership

Engaging families to impact health policies for CYSHCN

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

1



Today's
Objective:

Develop informed tactics for shaping the next generation of policymakers through parent advocacy and leadership

2

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.



3

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?



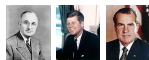
The Halo: <https://www.youtube.com/watch?v=3H50llsHm3k>

5

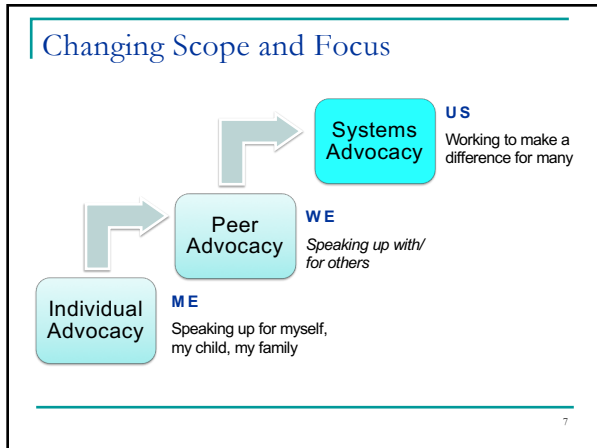
Knowing the Past to Change the Future

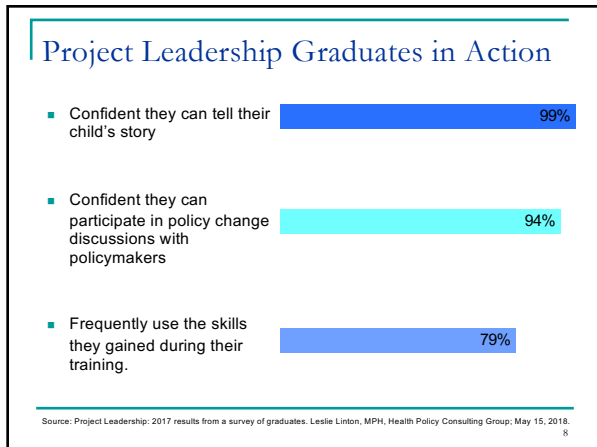


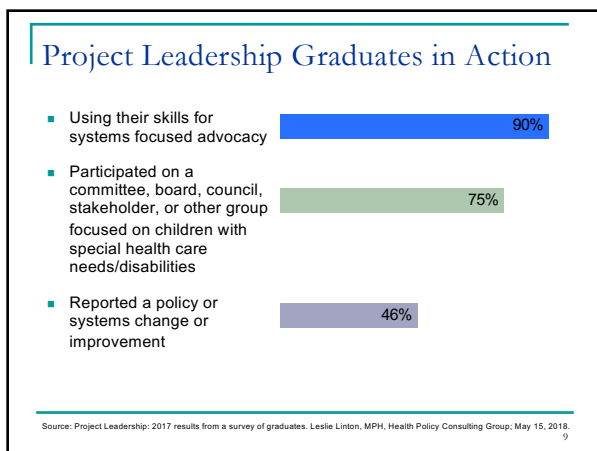
1920 1930 1940 1950 1960 1970 1980 1990 2000 2010



6







Nearly 2/3 of graduates
contacted their
legislators

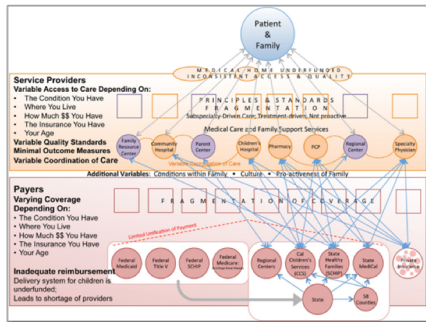


54% of these have
made in-person visits

Source: Project Leadership: 2017 results from a survey of graduates. Leslie Linton, MPH, Health Policy Consulting Group; May 15, 2018.

10

An Example: California's "System" of Care

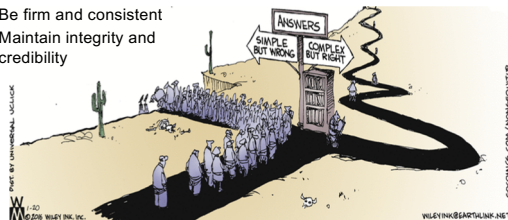


Source: Lucile Packard Foundation for Children's Health

11

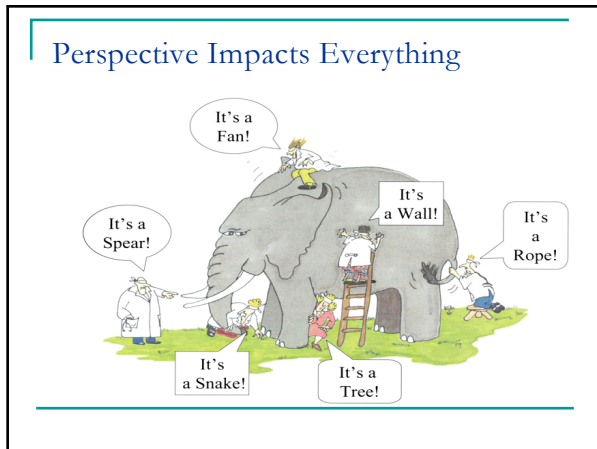
Developing the Action Plan


- Know what you want
- Get the facts
- Plan the strategy
- Gather support
- Be firm and consistent
- Maintain integrity and credibility




12

<p>Advocacy and Policy: Storytelling for Me</p> <p>Your Child's/ Loved one's first name: _____</p> <p>Your Relationship: _____</p> <p>Organization: _____</p>	
<p>1. YOUR CHILD'S/LOVED ONE'S NEEDS (Please check all that apply)</p> <p><input type="checkbox"/> General health care</p> <p><input type="checkbox"/> Specialty health care</p> <p><input type="checkbox"/> Prescription drugs</p> <p><input type="checkbox"/> Out-of-pocket medical expenses (deductible, co-pay, etc.)</p> <p><input type="checkbox"/> Mental health or substance abuse disorder</p> <p><input type="checkbox"/> Medical supplies (equipment, supplies, transportation)</p> <p><input type="checkbox"/> School accommodations</p> <p><input type="checkbox"/> Treatment therapy (e.g., chemotherapy, radiation)</p> <p><input type="checkbox"/> Other therapies (e.g., physical, speech, occupational)</p> <p><input type="checkbox"/> Mental education</p> <p><input type="checkbox"/> Access support</p> <p><input type="checkbox"/> Transportation to health appointments</p> <p><input type="checkbox"/> Socialization/Recreation</p> <p><input type="checkbox"/> Advocacy/Intervention</p> <p><input type="checkbox"/> Employment</p> <p><input type="checkbox"/> Community Inclusion</p> <p><input type="checkbox"/> Other: _____</p>	<p>2. WHAT HEALTH-RELATED SERVICES DOES YOUR CHILD/LOVED ONE RECEIVE?</p> <p><input type="checkbox"/> Medicaid</p> <p><input type="checkbox"/> Children's Health Insurance Program</p> <p><input type="checkbox"/> Health Savings Account</p> <p><input type="checkbox"/> Affordable Care Act (ACA) Marketplace insurance or private insurance</p> <p><input type="checkbox"/> No insurance</p> <p><input type="checkbox"/> Behavioral Intervention</p> <p><input type="checkbox"/> Transportation</p> <p><input type="checkbox"/> Case Management</p> <p><input type="checkbox"/> Other: _____</p>
<p>3. WHERE DOES YOUR CHILD/LOVED ONE RECEIVE SERVICES?</p> <p><input type="checkbox"/> At home</p> <p><input type="checkbox"/> Community-based organization</p> <p><input type="checkbox"/> Doctor's office</p> <p><input type="checkbox"/> Children's hospital</p> <p><input type="checkbox"/> General medical hospital</p> <p><input type="checkbox"/> Other: _____</p>	<p>5. FROM THOSE LISTED ABOVE, WHAT ARE YOUR TOP 2 CONCERNS?</p> <p>A. <u>Protect Affordable Care Act</u></p> <p>B. <u>Mental Health</u></p> <p>6. CHOOSE ONE TO FOCUS ON, FOR NOW: <u>Mental Health</u></p> <p>7. IN ONE SENTENCE, STATE THE OUTCOME YOU WOULD LIKE</p> <p><u>I would like... To get better and more accessible MH care and treatment at the school site, where things are triggered.</u></p> <p><u>Why is this important for YOU? My son needed mental health support at school.</u></p> <p><u>Why? He had serious mental health issues after bullying and mishandling, causing many health problems and lasting emotional problems.</u></p> <p><u>Why (did this happen)? There was no one he could trust at school and repeated incidents caused his condition to worsen.</u></p> <p><u>Why (did this happen)? There was no one on site with training or willingness to help.</u></p> <p><u>Why (was this a problem)? Only school-based intervention could address immediate situations and prevent crisis, damage, and suicide for students.</u></p> <p><u>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.</u></p>





Our stories help shape perceptions by bringing a powerful reality



15

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=JU1shouZ6g>

The Outline


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?	

Basic 8 for Developing Your Story	My Story
1. What is my purpose?	Explain how having a mental health professional on a school campuses can change lives
2. What outcome would I like?	I would like Assemblyman Kiley to co-author AB 8 (Chu)
3. What powerful examples do I have that I am willing to share?	<ul style="list-style-type: none"> • 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?	<ul style="list-style-type: none"> • Introduce my son & what happened • Explain how having a mental health professional at school helped him

Basic 8 for Developing Your Story	My Story
5. What visual aide, creative wording, "audience hooks" will I use?	<ul style="list-style-type: none"> Photo of my son on 1st day of 1st grade
6. What solutions or suggestions will I give my audience?	<ul style="list-style-type: none"> School mental health professionals understand the unique environment and can help resolve issues when they occur, and recognize and avert crisis
7. How will I close?	<ul style="list-style-type: none"> Thank you School therapist helped my son get through HS so he could go to his dream college Please co-author, help pass AB 8 to help others
8. What will I do if I get nervous?	<ul style="list-style-type: none"> Use notes/bullet points



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?

Great spontaneous appointment with Senator Pan and Dr. Dimand...

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.

FAMILY VOICES of California
elinn@familyvoicesofca.org familyvoicesofca.org

Interested in a Project Leadership Training?

Family Voices of California Project Leadership Manager Email List
elinn@familyvoicesofca.org #FV-PL-2020

Name	
Organization	
Position	
Phone	
City/State	
Type of Organization	
Comments	

22

Project Leadership Grads are Saying...



Cynthia Torres · Project Leadership Alumni Advocacy Group · 2 mins ·

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

Elaine Linn
 Family Voices of California
 Project Leadership Manager
elinn@familyvoicesofca.org
www.familyvoicesofca.org