

Project Leadership

What is Family Voices of California? Family Voices of California (FVCA) is a statewide collaborative of locally-based parent-run centers working to ensure quality health care for children and youth with special health care needs (C/YSHCN). FVCA provides information and a forum for parent centers and families to advocate for improved public and private policies, builds partnerships between professionals and families, and serves as a vital resource on health care. For more information visit familyvoiceofca.org.

What is Project Leadership? FVCA Project Leadership is a comprehensive training series that includes a seven-session training curriculum plus mentorship, information, assistance, and linkages with FVCA's statewide network. The project 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 in California on behalf of C/YSHCN. Training sessions are dynamic and interactive, offering parents the opportunity to learn with and from one another. The curriculum is best implemented as an entire series, but individual chapters may be used to conduct individual workshops.

Who is it for? Families and caregivers of C/YSHCN as well as the professionals who work with C/YSHCN.

What does it aim to do? The overall goal of Project Leadership is to increase the number of family members and caregivers of C/YSHCN who are prepared and supported to become advocates for health care policy and service improvements.

Expectations of Participants

- A desire to take on advocacy and leadership roles; commitment to and an enthusiasm for learning about the topics of advocacy, parent-professional partnerships, and family leadership.
- Participation in 6 of 7, or 85-90% of Project Leadership training sessions.
- A willingness to engage in a variety of learning activities and discussions.
- The ability to spend enough time outside of class doing research and completing assigned homework.
- An ongoing commitment to involvement in public policy advocacy on behalf of all C/YSHCN, including but not limited to active participation on health care- or disability-related committees, boards, councils, etc.; building relationships with legislators; or talking to the media

Expectations of Facilitators

- A commitment to, and an enthusiasm for the topic of advocacy.
- An adequate amount of time spent doing research and preparation before each training, including customizing training to the specific community.
- Flexibility and creativity in adapting information and activities to best suit the particular group of participants.
- Arrangement of local speakers for the final training session.
- **Collect and record training dates, training language, graduate names and contact information (phone, email address), and provide these to Family Voices of California 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.*

Contact Family Voices of California at info@familyvoicesofca.org or 415-282-7494
As of 12/14/18 the Project Leadership Manager is Elaine Linn, elinn@familyvoicesofca.org

Acknowledgements

The Family Voices of California Council would like to thank the Lucile Packard Foundation for Children’s Health for supporting the implementation of Project Leadership during its pilot year since it’s pilot year in 2013. The Foundation continues to provide funding as the project expands into its fifth phase. As of December 2018, nearly 70 Project Leadership trainers from 30 organizations in California and 1 each in Hawaii, Montana, and Oregon have graduated a total of 280 parents/caregivers of diverse racial, ethnic, socioeconomic, and linguistic backgrounds. Many graduates are participating on various health and disability-related boards and committees, meeting with legislators, and giving legislative testimony. The Council also thanks the Casey Foundation for supporting the development of the Project Leadership curriculum in 2004. With the generous support of these foundations, FVCA has been able to develop the capacity of families to take on leadership roles in their community and improve policies and systems of health care in California to better serve children with special health care needs.

The Family Voices of California Council would also like to acknowledge its members and staff, past and present, for their time and talent in the development of this project: Marta Anchonodo, Juno Duenas, Nancy Eddy, Reva Guimont, Allison Gray, Linda Joy Landry, Elaine Linn, Pip Marks, Al Millan, Patty Moore, Sherry Torok, JoAnna, Linda Vossler-Swan, and Kate Warren. The Council is especially grateful to Marta Anchonodo, Juno Duenas, Allison Gray, Linda Joy Landry, Sherry Torok, and Patty Moore for their tireless efforts in the completion of this manual. Finally, the Council thanks Project Leadership graduate Idell Wilson (San Francisco 2014) for her input on enhancing the cultural competency and addressing learning diversity throughout this manual.

For more information about this manual, contact:

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San Francisco County

Coordinating Office:

Support for Families of Children with Disabilities

1663 Mission Street, Suite 700

San Francisco, CA 94104

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Santa Barbara County

Alpha Resource Center

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Santa Barbara, CA 93110

(805)683-2145

Los Angeles County

Eastern Los Angeles Family Resource Center

1000 South Fremont Avenue

Suite 6050, Unit 35

Alhambra, CA 91803

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Alameda County

Family Resource Navigators

291 Estudillo Avenue

San Leandro, California 94577

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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 in California on behalf of children and youth with special health care needs (CYSHCN). To date, nearly 70 facilitators from 36 agencies and organizations have trained 280 family members. Project Leadership includes:

- A seven-session comprehensive training program.
- Linkages to local and statewide committees, task forces, and opportunities for input.
- Ongoing assistance and mentorship for program graduates, including membership to a statewide online Project Leadership Advocacy community.
- Opportunities to participate in regional and statewide health policy forums.

The **Lucile Packard Foundation for Children's Health** funds the Project Leadership program. Read more at <http://www.lpfch.org/publication/project-leadership-effecting-change-one-parent-time>.

The Project Leadership Training of Trainers

FVCA conducts two-day Training-of-Trainers workshops each year. These workshops are available to agencies and organizations serving or representing families of children with special needs. The workshop prepares participants to **implement the Project Leadership training and mentorship in their communities**. Participants learn best practices for implementing the training, and potential budgeting, and funding options.

Training of Trainer Selection Process:

Participants are selected through an application or nomination process. Selection is based on level of interest and willingness and ability to further *Project Leadership* goals and objectives.

Expectations of Agencies/Organizations and Trainers

- Commit to developing an action plan to implement Project Leadership.
- Be responsible for obtaining funding for local training series.
- Commit to recruit and train family members of children with special health care needs within 12 months of completing a Training-of-Trainers workshop.
- 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.
- Provide tracking data about trainings (i.e., Dates and locations of trainings, numbers of participants, evaluations, etc.) to FVCA, upon completing each training series.
- Link Project Leadership graduates to the FVCA statewide network, including a graduate database, the Project Leadership online Advocacy Community, alumni gatherings, and future conferences.
- Collect and record training dates, training language, graduate names and contact information (phone, email address), and provide these to Family Voices of California 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.

Notes for Facilitators about Leading Trainings

Family Voices of California (FVCA) grants permission for the printing and implementation of FVCA Project Leadership curriculum as long as FVCA is given credit. This curriculum is intended for use as a seven-session training series, or chapters can be used for individual training workshops. If you are using individual chapters, please present Chapter 0 prior to beginning the chapter session.

OVERALL EXPECTATIONS OF FACILITATORS:

- A commitment to, and an enthusiasm for the topic of advocacy.
- An adequate amount of time spent doing research and preparation before each training, including customizing training to the specific community.
- Flexibility and creativity in adapting information and activities to best suit your participants.
- Arrangement of local speakers for the final training session.
- **Collect and record training dates, training language, graduate names and contact information (phone, email address), and provide these to Family Voices of California 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.*

FACILITATOR NOTES:

- The “Facilitator Notes” are given to guide the Facilitator through each training.
- When the Notes are a script, questions to be asked, or something that can be read word-for-word, the text is in italics.
- When the Notes are just notes, bullet points, or something that facilitator does not have to read word-for-word, the text is normal (not italicized).
- The notes are guidelines- feel free to deviate from notes when you feel it is in the best interest of the group and the learning process.

TIME:

- Each training session should run approximately 4 hours long. This includes time for check-in, homework review, breaks, and evaluations.
- The activities are the only parts that have a suggested length given.
- It’s okay if certain activities take more or less time than what is suggested, just be sure to try and pay attention to the time so that the training doesn’t run too long.

MATERIALS & PRE-TRAINING PREPARATIONS:

- There is a list of materials and pre-training preparations (when applicable) given at the beginning of each chapter.
- Please be mindful of the chapters that have pre-training preparations.
- Chapters 1, 2, 3, 7
- Chapter 7 requires arranging 3 guest speakers in advance.
- For Chapters 1 and 5 there are extra materials that are located with the materials list for their respective chapters.

EVALUATIONS:

- Evaluations are done at the end of every chapter.
- Having participants complete evaluations is vital to improving this program in the future- please be sure to collect evaluations at the end of each training.

Contact Family Voices of California at info@familyvoicesofca.org or 415-282-7494.

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 – Detailed Table of Contents

CHAPTER 0

0.1 WHY DO WE DEVELOP PARENT LEADERS?

CHAPTER 1

- 1.1. HIGHLIGHTS OF KEY LEGISLATION & POLICIES
- 1.2. THE DISABILITY RIGHTS MOVEMENT
- 1.3. HIGHLIGHTS OF THE DISABILITY RIGHTS MOVEMENT
- 1.4. LEVELS OF ADVOCACY LEADERSHIP
- 1.5. DEVELOPING AN ACTION PLAN
- 1.6. MY ISSUES
- 1.7. CHAPTER 1 HOMEWORK

CHAPTER 2

- 2.1. GLOSSARY OF TERMS
- 2.2. POLICY
- 2.3. HOW POLICY WORKS
- 2.4. PUBLIC SYSTEMS FOR CHILDREN
- 2.5. LANDSCAPE: LEGAL MANDATES & AGENCIES FOR SERVICES FOR CSHCN
- 2.6. REFERRAL INFORMATION FOR CHILDREN WITH SPECIAL HEALTH CARE
- 2.7. REGIONAL CENTER/CA EARLY START
- 2.8. CALIFORNIA CHILDREN'S SERVICES
- 2.9. BEING AN ADVOCATE
- 2.10. POLICY PARTNERS AND ALLIES
- 2.11. MAKE A COMMITMENT!
- 2.12. CHAPTER 2 HOMEWORK
- 2.13. MAPPING OUR SYSTEMS
- 2.14. EVALUATION

CHAPTER 3

- 3.1. OUR ELECTED OFFICIALS
- 3.2. INFORMATION SOURCES
- 3.3. HOW A BILL BECOMES LAW: FILL IN THE BLANKS
- 3.4. HOW A BILL BECOMES LAW
- 3.5. HOW A BILL BECOMES A LAW
- 3.6. BUDGET PROCESS
- 3.7. TIPS ON GIVING EFFECTIVE LEGISLATIVE TESTIMONY
- 3.8. SAMPLE BILL: WORK LEGISLATIVE
- 3.9. WAYS TO COMMUNICATE
- 3.10. TIPS ON COMMUNICATING WITH ELECTED OFFICIALS
- 3.11. WRITING TO LEGISLATORS
- 3.12. VISITING YOUR ELECTED OFFICIALS
- 3.13. SAMPLE THANK YOU LETTER
- 3.14. TIPS ON MEDIA ADVOCACY
- 3.15. ACTION PLAN PRACTICE
- 3.16. CHAPTER 3 HOMEWORK

PROJECT LEADERSHIP – Detailed Table of Contents

CHAPTER 4

- 4.1. RECOGNIZING PERSONAL BEHAVIORAL RESPONSES: THOMAS-KILMANN CONFLICT MODE INSTRUMENTS
- 4.2. THOMAS-KILMANN CONFLICT MODE INSTRUMENT SCORE SHEET
- 4.3. THOMAS-KILMANN CONFLICT STYLES
- 4.4. MULTIPLE INTELLIGENCE TEST
- 4.5. VERBAL AND NON- VERBAL COMMUNICATION
- 4.6. COMMON INEFFECTIVE LISTENING BEHAVIORS
- 4.7. LISTENING SELF- ASSESSMENT
- 4.8. STRATEGIES FOR WORKING WITH PEOPLE WHO ENGAGE IN CHALLENGING BEHAVIOR
- 4.9. TOWN HALL COMMUNICATION ACTIVITY
- 4.10. CAN YOU TEACH YOUR CHILD TO BE A SELF- ADVOCATE? SHOULD YOU?
- 4.11. INVOLVING YOUR CHILD IN MEDICAL INTERACTIONS
- 4.12. CHAPTER 4 HOMEWORK
- 4.13. SAMPLE MEDICAL SHEET
- 4.14. TRANSITIONS- CHANGING ROLES FOR YOUTH
- 4.15. TRANSITIONS- CHANGING ROLES FOR FAMILIES
- 4.16. EVALUATION

CHAPTER 5

- 5.1. TIPS FOR A GOOD STORY
- 5.2. PEOPLE FIRST LANGUAGE
- 5.3. STORY DEVELOPMENT ACTIVITY 1
- 5.4. STORY DEVELOPMENT ACTIVITY 2
- 5.5. TELLING YOUR OWN STORY
- 5.6. EASY STEPS TO SUCCESSFUL PRESENTATIONS
- 5.7. GIVING A POWERPOINT PRESENTATION
- 5.8. BODY LANGUAGE ACTIVITY
- 5.9. CHAPTER 5 HOMEWORK
- 5.10. EVALUATION

CHAPTER 6

- 6.1. A PARENT’S GUIDE- SERVING ON BOARDS AND COMMITTEES
- 6.2. PLACES TO SERVE
- 6.3. PLACES TO SERVE CHART
- 6.4. CONTACT INFORMATION – PLACES TO SERVE
- 6.5. ARE YOU READY TO SERVE?
- 6.6. WHAT YOU NEED TO KNOW TO PARTICIPATE
- 6.7. HOW TO BE AFFECTIVE
- 6.8. PARLIAMENTARY PROCEDURE – ITS PURPOSE AND USE
- 6.9. GENERAL PRINCIPLES OF PARLIAMENT PROCEDURE
- 6.10. PARLIAMENTARY TERMS
- 6.11. A STANDARD AGENDA
- 6.12. SUMMARY OF STEPS IN HANDLING A MOTION
- 6.13. CHAPTER 6 HOMEWORK
- 6.14. EVALUATION

CHAPTER 7

- 7.1. OPPORTUNITIES FOR GRADUATES WITH FAMILY VOICES OF CALIFORNIA
- 7.2. EVALUATIONS

Project Leadership Learning Objectives

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

Learning Objectives

- Participants will be able to identify and understand important legislation and policies, especially as it pertains to their own lives and personal situations
- Participants will gain an understanding of the history of the Disability Rights Movement
- Participants will be able to identify and differentiate “advocacy” from “service”
- Participants will be able to identify different advocacy tactics used in different issue/advocacy situations
- Participants will be able to identify current issues of personal, regional and national importance/significance and possess the tools to research these issues independently
- Participants will gain experience building an Action Plan: identifying issues to be solved, goals and core constituencies

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

Learning Objectives

- Participants will define and differentiate “laws,” “statutes,” “regulations,” and “entitlement programs”
- Participants will distinguish whether policy problems stem from the intent/language of the law, regulation/ruling explaining how the law is implemented, and the law’s implementation
- Participants will identify the three branches of government and differentiate between local, state and federal government/policy
- Participants will demonstrate knowledge of public systems for children, the mechanism for funding these programs and the agencies responsible for implementing services
- Participants will differentiate between individual advocacy and policy/systems advocacy
- Participants will identify partners and allies in the advocacy process

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

Learning Objectives

- Participants will know how to obtain information about their elected officials
- Participants will demonstrate knowledge of how bills become laws in the model Congress session
- Participants will understand the levels, and the three branches of government
- Participants will understand the regulation and implementation phases of lawmaking
- Participants will understand the budget process and how it directly affects them
- Participants will gain the skills to effectively communicate with their elected officials via email, telephone call, letter or personal visit
- Participants will possess the skills necessary to give effective public testimony
- Participants will learn how to effectively utilize the media to advocate

Project Leadership Learning Objectives

Chapter 4: Playing Well with Others: Enhancing Communication

Learning Objectives

- Understand different personal communication styles
- Understand the importance of listening
- Learn about working with different types of people – all with different communication and listening styles – and move past conflicts that arise
- Understand the importance of involving your child in the decision-making process, ensuring they will be able to advocate for themselves

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

Learning Objectives

- Participants will understand the importance of storytelling
- Participants will be knowledgeable about how to develop a good story, using appropriate and respectful language, organization of information, and goals of the story
- Participants will know their presenting style, be aware of their body language during presentation, and know their boundaries when presenting
- Participants will feel confident in their ability to present and evaluate their stories, and will demonstrate this ability
- Participants will know how to develop and present a “One-Minute Story”, and will be able to demonstrate this ability

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

Learning Objectives

- Participants will learn about the value of participating in decision making bodies
- Participants will recognize that, as family members, they offer a unique perspective and unprecedented knowledge about CSHCN
- Participants will become familiar with the variety of places they can serve
- Participants will know how they can plan for success in their participation
- Participants will know the different types of decision-making (majority rules, decision-maker, and consensus)
- Participants will understand the rules for participation through their gained knowledge of parliamentary procedure and the standard agenda

Chapter 7: Solidifying Partnerships: Connecting with Local Change Makers

Learning Objectives

- Participants will learn how to connect with local leaders and advocates
- Participants will gather specific information about advocating for CSHCN from each of the guest speakers
- Participants will present their completed Action Plans, and as peers review their Action Plans, participants will gain an even better understanding of what an effective Action Plan should consist of