

Family Voices of California Project Leadership

An Innovation Station Practice

Purpose: This document is intended to support MCH professionals to implement a practice found in Innovation Station. This resource provides the information needed to replicate the practice and is divided into two sections: the first section provides a high-level overview of the practice while the second section describes how to implement the practice. For additional information on any of the content provided below, please reach out to the practice contact located at the bottom of this document.

Section I: Practice Overview

Location:	California	Title V/MCH Block Grant Measures Addressed
Category:	Promising	NPM #06: Percent of children, ages 9 through 71 months, receiving a developmental screening using a parent completed screening tool NPM #11: Percent of children with and without special health care needs having a medical home NPM #12: Percent of children with and without special health care needs who received services NPM #15: Percent of children 0 through 17 years who are adequately insured
Date Submitted:	11/2016	

Practice Description

The vision of Project Leadership is that families of CYSHCN and consumers will be able to effect health care program improvement, systems change, and lasting reforms. The overall goal of this project is to increase the number of family members of CYSHCN who are prepared and supported to become advocates for health care policy and service improvements.

Purpose

The systems designed to serve children and youth with special health care needs (CYSHCN) in California are complex and difficult to navigate. Policy makers, health care decision-makers, administrators of social service agencies and managers of health care institutions often lack a full understanding of the difficulties families face in accessing health care services for their children with special needs.

It is critical that policy makers and health care administrators hear directly from families of CYSHCN and from consumers so that they can obtain an accurate, “real world” view of the impact of legislation, policy, and administrative procedures. With training and support, families

with experience navigating health care systems and services have tremendous potential to advocate for improvements and effect change on both local and state levels.

Family Voices of California (FVCA) formulated the Project Leadership curriculum and mentoring program to meet the unique challenges of California's size and its highly diverse population of families of CYSHCN. Project Leadership was designed to help family members develop the skills and resources they need to partner at all levels and to engage in public policy advocacy activities in California on behalf of CYSHCN. Project Leadership is comprised of a seven-session comprehensive training curriculum plus support services that include mentorship, information, and linkages with FVCA's statewide network.

In 2013, FVCA received funding from the Lucile Packard Foundation for Children's Health to pilot the training series; the foundation has continued to provide support as the project has expanded into its fourth phase. To date, approximately 150 parents / caregivers of diverse racial, ethnic, socioeconomic, and linguistic backgrounds have completed or are currently participating in the training series around the state in Alameda, Los Angeles, Napa, San Bernardino, San Diego, San Francisco, and Santa Barbara counties.

The vision of Project Leadership is that families of CYSHCN and consumers will be able to effect health care program improvement, systems change, and lasting reforms. The overall goal of this project is to increase the number of family members of CYSHCN who are prepared and supported to become advocates for health care policy and service improvements. Specifically, graduates will:

- participate on committees and boards at all levels of the service system, including (health plans, hospitals, MediCal, county health programs, state-level committees);
- meet with local, state, and federal policymakers and system administrators to advocate for specific legislation and service improvement;
- provide public testimony; and
- present their stories to the media.

Project participants are parents/caregivers of families from diverse backgrounds whose children have special health care needs, using The Maternal and Child Health Bureau definition: "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Practice Foundation

The initial approach for Project Leadership grew out of Partners in Policymaking California (PIPICA), an affiliate of Minnesota's internationally recognized program that provides competency-based leadership training for adults with developmental disabilities and parents and care partners of young children with developmental disabilities. In partnership with The Arc of CA, CA Association of Family Empowerment Centers, People 1st of CA and the Family Resource Centers Network of CA, PIPICA offered a 130-hour certificated program for families and consumers that took place during eight weekend sessions—one each month for eight months—and had a strong focus on influencing legislative policy at the state level. Sessions

required an overnight stay of participants. There was one PIPCA session per year in one of four regions (north, central, south, Los Angeles County). (PIPCA is no longer active in the state.)

FVCA wanted to develop a training that would make family participation easier: one that would be less time-intensive and not require overnight stays, which can be challenging for parents of CYSHCN. FVCA also wanted to broaden eligibility to families who wouldn't qualify for PIPCA under its developmental disability criteria. Unlike PIPCA, which is focused on state legislation, FVCA also wanted to promote advocacy at local and regional levels as well as the state level, and prepare families to work effectively with health care providers for systems change.

FVCA met with PIPCA, as well as two other successful leadership models: the Arizona Department of Health Services, Office for Children with Special Health Care Needs; and the Florida Institute for Family Involvement. The organizations discussed their models, and identified strengths and challenges. As a result, FVCA formulated a model that would work best for California's CYSHCN, considering the size and diversity of the state

Core Components

Project Leadership Curriculum Over the seven sessions of the Project Leadership training curriculum, families learn about legislative and healthcare systems, develop the skills they need to frame their stories as they talk to legislators and key stakeholders, and prepare to communicate effectively with the media. The Project Leadership curriculum is available in English, Spanish, and Chinese. The curriculum was developed with family input and refined over several years. Using participant evaluations, feedback from local Trainers / Mentors, an external evaluation conducted during Phase I, and consultation with Project Leadership graduates, the curriculum was updated and enhanced to be more culturally competent and to better reflect the diversity of the training participants. Additional materials, activities, and types of media were incorporated to accommodate a range of learning styles. Revisions are made to the curriculum on an on-going basis to reflect policy / regulatory updates.

Training of Trainers The Project Leadership Manager, who is responsible for managing all project activities statewide, facilitates Training-of-Trainers workshops. A Request for Applications is disseminated throughout the state inviting agencies and organizations serving CYSHCN to apply to send one representative to the workshop. At the workshop, participants learn about the curriculum content and best practices for implementing the training, and they receive information on how they might approach local foundations and funders. Each participant is also responsible for developing an Action Plan that outlines how the Project Leadership model will be implemented in their local area.

Mentoring and Support Based on the experiences and feedback from project participants, key to the success of this project is the mentoring and ongoing support that is provided to parents / caregivers who complete the Project Leadership training. Mentoring and support activities available to parent / caregiver graduates include participation in:

- The Project Leadership Online Advocacy Community in which alumni stay informed and updated on local and state policy issues and involvement opportunities. This forum helps keep graduates connected and facilitates peer mentoring. Participants are encouraged to post their own advocacy updates and to support each other in their advocacy pursuits.
- Regular webinars that feature guest speakers who provide information on current issues or train / refresh graduates on skills that will help to improve their leadership and advocacy

efforts. These sessions may also include continuing education and updates on state and regional policy issues affecting CYSHCN.

- Annual in-person alumni meetings to offer additional education, support, and networking opportunities. These include an Annual Alumni Meeting Northern California, an Annual Alumni Meeting Southern California, and the FVCA Annual Health Summit held in Sacramento.
- Mentoring and support from local Family Resource Centers to address personal issues that arise involving the needs of their children.

In addition, FVCA provides coordination of the growing statewide network of parent leaders and linkages to involvement opportunities. All these supports are critical in helping participants remain engaged and effective public policy advocates.

Evidence of Effectiveness (e.g. Evaluation Data)

Health Policy Consulting Group completed an evaluation of the first training groups from San Diego and San Francisco and documented the positive impact of the project:

- From surveys before and after training, participants showed significant, positive change on measures of empowerment for accessing services for children and participating in community and political issues;
- When tested at the end of their training, participants' confidence in their ability to advocate, their leadership skills, and their experience with advocacy showed significant improvement;
- By two months after the training, 87% of participants had joined or identified a health care or disability related organization, advocacy group, task force, or committee. At the two-month mark, 61% had participated in a decision-making process affecting CYSHCN and an additional 18% had identified an opportunity for the future.

FVCA continues to incorporate the tools and suggestions of Health Policy Consulting Group to assess program outputs, program quality, and program impact. FVCA surveys project participants, both graduates and local Trainers / Mentors, to assess program quality, effectiveness, impact, and to help identify additional needs for training and / or support. Surveys include curriculum surveys for both the Project Leadership training and the Training-of-Trainers workshop, webinar surveys, and in-person event surveys.

In Phase IV, with the consultation of an external evaluator, FVCA conducted an intensive follow up with graduates to obtain updated information on their leadership and advocacy activities, to identify the impact of their activities, and to better understand if their participation has been meaningful:

- 89% of graduates report using the skills learned from Project Leadership in their work with committees, boards, decisionmakers, media or in other leadership roles
- 65% of graduates report having been a member of a committee, board, council, stakeholder group, taskforce, or any other group focused on children with special health care needs/disabilities during the year preceding the survey.
- 64% of graduates are "very confident" that they can tell their child's story in a way that informs people with decision-making power about why they need to change policies and systems. 35% reported they are "somewhat confident."

Replication

The Project Leadership Training-of-Trainers workshops, the availability of project materials on the FVCA website, and the technical assistance provided by the Project Leadership Manager to local Trainers / Mentors have facilitated replication of the trainings throughout the state.

Agencies outside of California that have requested information about the project include Family Voices National; Parents, Let's Unite for Kids (Family Voices State Affiliate Organization in Montana); Iowa Family Leadership Training Institute; Stone Soup Group (Family Voices State Affiliate Organization of Alaska); and Noah's Ark of the Shoalhaven, West Nowra Australia. The curriculum is adaptable to meet the needs of a particular target population or to the systems and services of different states, and there are plans in place to bring the curriculum to both Texas and Ohio in 2021.

Section II: Practice Implementation

Internal Capacity

Trainer

The Project Leadership trainer is responsible for all aspects of the 7-part Project Leadership series, including participation in a Training of Trainers, planning and facilitation of the series, and post-training activities outlined in the training of trainers including providing a post-training summary with graduate contact information.

Role of the trainer

- **Instruct and empower.** Facilitators should empower and equip individuals to apply personal experiences to make *systems* improvements rather than “solving” problems or advocating for them.
- **Ask questions.** Model Project Leadership skills by asking probing questions requiring resourceful thinking.
- **Engage and inspire.** Take advantage of the dynamic and interactive curriculum to engage participants rather than “talking at them.”
- **Protect confidentiality.** Enforce a strict confidentiality rule to create a safe environment for everyone.
- **Respect various perspectives and model humility.** Participants come from different backgrounds and have varying degrees of education, knowledge, and experience. Create a mutual “code of conduct” at the beginning (e.g., respect others’ opinions, equal sharing time) to cultivate a richer experience.

Important skills

- **Group management** – Engage the group and give everyone an equal opportunity to contribute without allowing anyone to dominate.
- **Time management** – Stick to a schedule while being flexible based on the interests, knowledge, and experience level of the group. You may adjust times within a session but don't end late.
- **Questioning / Listening / Responding** – Ask open ended questions and prompt participants to expand answers. Demonstrate active listening, clarifying when you don't

understand and paraphrasing answers to show understanding, providing supportive feedback, and respect for feelings.

- **Conflict resolution.** Discussions may get intense. Practice what Project Leadership teaches by requiring and modeling respect for differing opinions. Be prepared to re-direct if things get too heated.
- **Pay attention to different learning styles.** The curriculum includes various formats and activities to present information. Tune in to your participants to determine what works best for the group.
- **Conduct regular evaluations.** Use periodic check-ins at the end of chapter evaluations to find out what could be improved. Implement feedback in future sessions when applicable.

Graduate Mentor

The Project Leadership graduate mentor builds skills and motivates graduates to discover, plan, and advocate for themselves and other families for systems change.

During Training

- Available upon request
- Reviews action plans and provides feedback
- Connects participants with common interest, issues,
- Conducts individual or small group check in outside of training sessions
- Matches previous graduate to current participants for peer mentorship

Post-Training

- Available upon request
- Publicizes calls to action and opportunities for advocacy
- Tracks graduate placements and share with FVCA
- Keeps graduates updated on FVCA activities
- Provides direct outreach to graduates who have expressed interest in a particular opportunity
- Provides policy updates, new skills, and recognizes graduate activities in publications and social media
- Assists with applications, letters of recommendation, etc.
- Organizes in-person activities, discussions, etc.
- Attends FVCA annual alumni meetings and the Health Summit & Legislative Day in Sacramento and acts as a group leader for their organization's graduates
- Conducts annual meetings/reunions with continuing education and a networking opportunity

Depending on their capacity, many organizations have one staff member who takes on both roles; however, employing two staff members to divide these roles would provide the opportunity for more frequent training sessions and more robust mentorship.

Supports:

The Project Leadership Manager at Family Voices of California provides a menu of technical assistance options to assist participating agencies and organizations in implementing the trainings and developing and maintaining leadership activities in their regions. These include, for

example, an email group for local Trainers / Mentors; problem solving with the Project Leadership Manager via phone or email; quarterly conference calls with local Trainers / Mentors statewide, site visit and consultation with the Project Leadership Manager.

The Family Engagement Manager at Family Voices of California provides a central point of dissemination of opportunities for graduates to put their advocacy skills to use, serves as an additional point person for support around the advocacy activities of graduates, and plans and facilitates annual Project Leadership Alumni events.

Collaboration/Partners

FVCA collaborates with FVCA Council Member Agencies, the Family Resource Center Network of California, and the Lucile Packard Foundation for Children’s Health to identify additional opportunities and resources for training and advocacy resources and help families link to them.

Local representatives from various state and county agencies (e.g. California Children’s Services, Regional Center, State Council on Developmental Disabilities) and other community-based organizations serving CYSHCN have submitted applications for the 2016 Training-of-Trainers workshops. FVCA looks forward to collaborating with these agencies on their family engagement efforts.

Practice Cost

The costs for implementing the Project Leadership series vary greatly depending on an agency’s existing resources. Potential costs include local Trainer / Mentor salary, training space, materials, stipends, childcare, and food.

Practice Timeline

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Phase	Description of Activity	Date/Timeframe	# of hours needed to complete/oversee activity	Person(s) Responsible
Planning/ Pre-implementation	Participation in Training of Trainers	Formats vary, usually 2 full days	16	Trainer(s), Mentor(s)
	Finalize training details (identifying funding, organizational partners, participant outreach and enrollment)	Approx. 4 weeks before planned training	25 hours	Trainer(s), Mentor(s)
	Finalizing training logistics (meeting place, meal(s) provided, childcare, interpretation needs,	Approx. 2 weeks before planned training	20-30 hours	Trainer(s), Mentor(s)

	preparing training materials			
	Learning and reviewing curriculum	Varies depending on familiarity with training content	7-35 hours	Trainer(s), Mentor(s)
Implementation	Preparation for each session (preparing materials, incorporating evaluation feedback into training plan, logistics)	Weekly	5-10 hours per session, 35-70 hours total	Trainer
	7 Project Leadership sessions, one for each chapter of the curriculum	Dependent on capacity of participants and facilitators; weekly or biweekly sessions are recommended	6 hours per session (includes 2 hours of set up and clean up), 42 hours total	Trainer
	Mentoring outside of training session	Approx. 1hr/week/participant	Approx. 7 hours per participant	Trainer
Sustainability	Provide ongoing mentoring to PL graduates	Ongoing	Varies	Mentor

Resources Provided

The Project Leadership curriculum is available at <http://www.familyvoicesofca.org/project-leadership/>.

For more details about the project, please refer to Project Leadership: Effecting Change, One Parent at a Time (June 2015) published by the Lucile Packard Foundation for Children's Health. (<http://www.lpfch.org/publication/projectleadership-effecting-change-one-parent-time>)

The full 2018 Graduate Survey report is available at <http://www.familyvoicesofca.org/wp-content/uploads/2020/01/2018-Graduate-Survey-Report-1.pdf>.

Lessons Learned

Awareness of Project Leadership and the value of parent participation grow as graduates continue to provide public testimony; speak on parent panels; build relationships with their legislators; tell their stories to the media; and serve on boards, committees, and other advocacy groups.

The growing expectations and/or mandates for parent involvement in decision-making and/or advisory roles indicate a greater need for more parents be trained and for more agencies to be prepared to implement the training. FVCA Project Leadership is working to fulfill this need. Now at the beginning of its fourth grant cycle, Project Leadership continues to make progress towards our long-term goal of supporting parents to partner with professionals, to have their voices heard on a variety of advisory and decision making groups, and to engage in public policy.

Primary challenges and potential barriers include:

1. Participation of parents and family members of CYSHCN can sometimes be a challenge because of the time they need to care for their families.
2. California is a highly diverse state and requires close attention to the cultural and learning needs of participants. The Project Leadership Manager collaborates with past and future local host sites that know and understand the needs of their local communities. Outreach to families from underserved populations will continue to be a priority.
3. California's Department of Health Care Services as well as other state, county, and local agencies serving CYSHCN have limited experience in engaging families on committees and task forces.

Overcoming Challenges

1. Project Leadership and partnering agencies offer a variety of ways that families can access information, support, and resources. These include the Online Advocacy Community, live and recorded webinars or teleconferences, and an annual in-person meeting. FVCA understands the importance of accommodating families and offering incentives such as childcare, travel reimbursements, and stipends to cover the costs of participating. These kinds of incentives have been instrumental in recruiting and retaining a diverse group of parents. Access to support from local Family Resource Centers is also key in ensuring that families' personal needs are being met.
2. The Project Leadership Manager collaborates with past and future local host sites that know and understand the needs of their local communities. Outreach to families from underserved populations continues to be a priority.
3. One of the jobs of the project management is to encourage and support these agencies to institutionalize parent partnership

FVCA has learned some practical lessons that others interested in implementing the curriculum may want to consider:

- Flexible scheduling, childcare and stipends all proved important in recruiting and retaining participants.
- The long-term mentoring and the facilitated peer support among program graduates have been essential for continued motivation and engagement of graduates.
- Offering a variety of means for communication, mentoring and support helped ensure that all graduates' needs were met.
- The online forum kept graduates informed about opportunities for involvement beyond their local areas and helped develop a sense of community with a larger network of families advocating on behalf of CYSHCN.

- FVCA also learned that in order to build on family partnership and encourage growth of parent opportunities, FVCA and host site agencies need to educate more policy-making agencies about the importance of including families, developing guidelines for family involvement, and removing barriers to family participation.

Next Steps

The goal for Phase V of the project is to continue to build a strong, statewide learning community with mentoring and support that helps ensure that family members of CYSHCN are prepared to become advocates for health care policy and service improvements. FVCA has expanded outreach to the Training-of-Trainers workshop beyond Family Resource Centers to all agencies serving CYSHCN and will soon be expanding to Ohio and Texas. In addition, in light of COVID-19, FVCA is working to develop methods of bringing parts of Project Leadership online so that families can benefit from the curriculum without having to attend a 7-part, in-person training that is now inaccessible to many due to social distancing recommendations and the medical fragility of their families during the pandemic.

Practice Contact Information

For more information about this practice, please contact:

Name: Elaine Linn, FVCA Project Leadership Manager

Number: 916-799-6438

Email: elinn@familyvoicesofca.org