

Family Voices of California Project Leadership

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 Category: **Promising Practice**

BACKGROUND

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.

TITLE V/MCH BLOCK GRANT MEASURES ADDRESSED
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| <p>#06 Percent of children, ages 9 through 71 months, receiving a developmental screening using a parent-completed screening tool</p> <p>#11 Percent of children with and without special health care needs having a medical home</p> <p>#15 Percent of children 0 through 17 years who are adequately insured</p> <p>#12 Percent of children with and without special health care needs who received services necessary to make transitions to adult health care</p> |
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PROGRAM OBJECTIVES

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, Medi-Cal, 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;
- present their stories to the media.

TARGET POPULATION SERVED

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.

PROGRAM ACTIVITIES

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 and Spanish.

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 a Training-of-Trainers workshop in Northern California and one in Southern California each year of the current project grant (winter 2016 and winter 2017). 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.

The Project Leadership Manager 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.

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.
- Quarterly 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.
- On-going individual mentorship by the Project Leadership Manager via phone, email, or in-person meetings. The local Trainer / Mentor is also available to mentor graduates in their leadership / advocacy pursuits.
- 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 of these supports are critical in helping participants remain engaged and effective public policy advocates.

Database of Family Leaders

The Project Leadership Manager maintains the FVCA database of family leaders. This database helps match trained family leaders with agencies or media seeking input. It also serves as a way to track advocacy activities of project alumni. The database is available to agencies and policy makers through contact with FVCA.

Opportunity Database

The Project Leadership Manager also maintains an opportunity database that contains information for family involvement in health care policy and decision-making throughout the state. The database is used to help local Family Resource Centers and other agencies identify involvement opportunities for their families



PROGRAM OUTCOMES / 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:¹

- 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 will be conducting 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. FVCA will also survey past graduates to identify the factors that have helped them stay involved and engaged.

PROGRAM 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.

ASSETS & CHALLENGES

Assets

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.

Challenges

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

¹ Health Policy Consulting Group *Evaluation Report: Project Leadership*, prepared for the Lucile Packard Foundation for Children's Health and Family Voices of California, May 31, 2014.



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 and shared decision-making in a meaningful way.

LESSONS LEARNED

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.

FUTURE STEPS

The goal for Phase IV 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. In addition, FVCA is working with agencies already trained and prepared to implement Project Leadership on how to make this training a sustainable, on-going component of their parent training programs. There is also an increased emphasis on tracking graduate activities,

and FVCA will be consulting with an external evaluator on this effort.

COLLABORATIONS

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.

PEER REVIEW & 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.

RESOURCES PROVIDED

The Project Leadership curriculum is available to download 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/project-leadership-effecting-change-one-parent-time>)

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Family Involvement, CYSHCN

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