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PROJECT LEADERSHIP: 2018 RESULTS FROM A SURVEY OF GRADUATES

PREPARED FOR: FAMILY VOICES OF CALIFORNIA
BY: LESLIE S. LINTON
HEALTH POLICY CONSULTING GROUP



Key Findings: *Project Leadership* 2018 Results from a Survey of Graduates

Funded by The Lucile Packard Foundation for Children's Health, *Project Leadership* is a parent advocacy training with the overall goal of increasing the number of family members of children with special health care needs who are prepared and supported to become advocates for health care policy and service improvements. *Project Leadership* is a program of Family Voices of California (FVCA). A survey of program graduates was fielded in 2018, and this report summarizes results.

Current use of skills learned in training.

- 89% of graduates report using the skills learned from *Project Leadership* in their work with committees, boards, decisionmakers, media or in other leadership roles (60% "frequently" and 29% "occasionally.")
- 96% of graduates use the skills acquired from the training in advocating for their children (66% "frequently" and 30% "occasionally.")
- During the year preceding the survey, 58% of graduates contacted their legislators. Of those who had contacted legislators, 82% reported having done so on multiple occasions and 57% did so via an in-person visit.
- During the year preceding the survey
 - 10 graduates provided interviews to the media.
 - 21 graduates provided testimony or public comment.
 - 33 graduates were speakers or presented as part of a panel.
- 21 graduates report that their Project Leadership acquired skills have assisted them in performing the responsibilities of their job; 6 additional graduates report that their Project Leadership skills directly led them to their job.

Participation as a member of groups.

- 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.
- Graduates felt their presence in these groups has made a difference, with an average satisfaction rating of 4.6 on a scale of 1-5. They rated their sense of satisfaction from participating in the group as 4.7.
- For the 107 groups that graduates were members of during the previous year, graduates reported
 - 31% of groups underwent policy or systems change or improvement.
 - An additional 62% of groups either had policy or systems change under consideration or decisionmakers have indicated greater understanding and change may be possible in the future.

Confidence in advocacy ability.

- 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.”
- 46% of graduates are “very confident” that they can participate in policy change discussions with decisionmakers. 43% reported they are “somewhat confident.”

Mentoring and support services provided by FVCA.

- An important component of the program is ongoing mentoring and support of graduates seeking to use their Project Leadership training. More than 87% of graduates participated in one or more of these activities, and all graduates receive regular communications, resources, and updates from the program.
- Ongoing support services are highly valued by graduates. Among those who participated, high proportions of graduates rated activities very useful or somewhat useful to them, including individual email and telephone contacts (96%), FVCA Health Summit and Legislative Day in Sacramento (94%), social media support (Facebook group) (93%), conference calls with staff (93%), annual in-person gatherings (93%), email and phone connections with other graduates (91%), and webinars (90%).

Demographics: a diverse group.

- 39% of graduates identified themselves as Hispanic/Latino, 38% as White/Non-Hispanic, 14% as African American, and 12% as Asian/Pacific Islander.
- 33% of participants reported family income of \$46,000 or less, and 32% reported income in excess of \$100,000.
- 93% of graduates reported at least “some college.”
- Graduates reported about services and agencies used by their families. 81% use Medi-Cal, 73% use Regional Center, 53% have private insurance, 51% receive In-Home Supportive Services and 33% are CCS beneficiaries.

Survey participation.

- The survey was fielded in July and August of 2018 among English speaking graduates and in September through November among Spanish speaking graduates (in Spanish).
- At that time, there were 189 graduates from *Project Leadership* training since the program’s beginning in 2013.
- FVCA sent the survey to 177 graduates for whom there was current contact information. Survey responses were received from 83 graduates. The response rate was 47%, overall. The response rate was 48% among English speaking graduates (75 responses) and 36% among Spanish speaking graduates (8 responses).

Conclusions and recommendations.

- 99% of graduates said that they were likely to recommend the *Project Leadership* training to a parent of a child with special health care needs / disabilities.
- Survey results demonstrate that graduates are actively engaged following training through membership in groups and participation in other advocacy activities. Continuing to make the training available to families of children with special health care needs / disabilities should be a priority.
- The ongoing support and mentorship of graduates by FVCA, is likely playing a strong role in maintaining advocacy activity by graduates and should continue. Exploring ways to expand support capacity through local trainers should also be considered. Continuing to find ways to support underrepresented families should be supported.
- Continue evaluation efforts, particularly as the program continues to evolve. Collecting data from organizations where *Project Leadership* graduates are participating is a logical addition to evaluation efforts and may document systems and policy changes as well as the value of family engagement.

The evaluation report that follows summarizes the results of a 2018 survey of graduates from Family Voices of California's (FVCA) *Project Leadership* parent advocacy training program. It also includes a summary of interviews of three program graduates. The interview protocol was designed to learn more about how graduates have used their advocacy skills and how they are supported by FVCA after graduation.

INTRODUCTION.

As described on the Family Voices of California (FVCA) website, "*Project Leadership* is a parent advocacy training whose overall goal is to increase the number of family members of children with special health care needs who are prepared and supported to become advocates for health care policy and service improvements. The *Project Leadership* curriculum introduces parents and caregivers to the nuts and bolts of advocacy in a seven-session training series. The program is funded through a grant from the Lucile Packard Foundation for Children's Health."

The *Project Leadership* curriculum and training was initially piloted and evaluated with two cohorts of parents/caregivers in San Diego and San Francisco in 2013 and 2014. Since then, the program has grown significantly. Beginning in 2015, the program launched a train-the-trainer model in order to expand capacity. By the summer of 2017, when a graduate survey was first fielded, the program had graduated 144 advocates. By the summer of 2018, when the survey that is the subject of this report was fielded, there were 189 graduates. Since then, the program has continued to grow. FVCA reports that as of June 21, 2019, FVCA has trained 103 facilitators from 60 organizations. As of the same date, nearly 300 family members have graduated from the program. In the current (2019-2020) phase, FVCA is building training capacity with additional organizations throughout California, and expanding trainers workshops throughout the U.S. FVCA continues to support all trainers and California graduates as they complete the program.

Beginning in 2017, the program developed a survey of *Project Leadership* parent graduates to track relevant graduate activities and measure the impact of those activities, as well as to inform staff about how to best provide ongoing mentorship of program graduates. In collaboration with *Project Leadership* staff, an evaluation consultant at Health Policy Consulting Group constructed a survey in SurveyMonkey that was later fielded by *Project Leadership* staff. A report dated May 15, 2018 and titled "*Project Leadership: 2017 Results from a Survey of Graduates*" summarized results from the 2017 survey of program graduates.

FVCA's *Project Leadership* staff planned a new survey of program graduates for the summer of 2018. Again working with Health Policy Consulting Group, the program revised and added to the 2017 survey. Some questions were maintained in identical format, including those about active use of skills and self-ratings of confidence concerning specific acquired skills (these questions dated to the original evaluation of the pilot), and these questions have allowed comparisons over time. Several questions were clarified and further refined, and some demographic questions were added:

- to include information about the health insurance coverage and service programs accessed by graduate families on behalf of their children/youth with special health care needs (CSHCN);
- to include information about the nature of graduates' childrens' health and disability challenges; and
- to include information about employment and potential relevance of Project Leadership skills in graduates' job performance.

The consultant constructed the 2018 survey, again, in close collaboration with *Project Leadership* staff, on the SurveyMonkey platform. The survey is included in the Appendix to this report. *Project Leadership* staff had the survey translated into Spanish. Both versions of the survey were tested and then fielded with graduates by *Project Leadership* staff. In July, 2018, a link to the English version in SurveyMonkey was sent to graduates for whom the program had valid contact information. English version surveys were collected in July and August of 2018. A link was sent to Spanish-speaking graduates and surveys were collected online from September through November 2018.

Both versions of the survey included an incentive – the award of \$50 for 4 people, randomly drawn from among those who completed the survey.

RESPONSE RATE.

Response rate information for both the 2017 survey and the 2018 survey are included in Table 1, below. As of the 2018 administration, there were 189 graduates recorded by the program. Valid contact information was available for 155 English speakers, 22 Spanish speakers, and one Chinese speaker. Surveys were completed in English by 75 respondents and in Spanish by eight respondents. The overall response rate was 47%. The response rate was 48% for English speakers and 36% for Spanish speakers. *Project Leadership* staff believe the higher response rate in 2017 may have been a reflection of the smaller size of the program at the time, and the fact that many of the graduates then had been personally trained by FVCA staff, who also fielded the survey.

Table 1. <i>Project Leadership</i> Survey Response Rate								
	2017				2018			
	# Grads	Valid contact info	Survey responses	Response rate	# Grads	Valid contact info	Survey responses	Response rate
Total Graduates (as of survey administration)	144				189			
English speakers	118	114	82	72%	161	155	75	48%
Spanish speakers	25	17	12	71%	27	22	8	36%
Chinese speaker	1	N/A			1	N/A		
Overall		131	94	72%		177	83	47%

RESULTS.

Demographic information.

Table 2, below, includes a summary of self-reported demographic information. It also includes data from the 2017 graduate survey, where available, for comparison purposes. The overwhelming percentage of graduates were female (95% in 2018). Self-reported ethnicity/race closely resembles data from 2017. And, these data are strikingly similar to statewide data describing children with special healthcare needs, reported in Table 3.¹

Table 2. Project Leadership graduates: self-reported demographics				
	2017 (N=94)		2018 (N=83)	
Gender (2017:n=90; 2018 n=74)	No. respondents	Percentage	No. respondents	Percentage
Female	83	92%	70	95%
Male	7	8%	4	5%
Ethnicity/race (2017 n=88; 2018 n=74)				
Hispanic/Latino	34	39%	29	39%
White / non-Hispanic	27	31%	28	38%
African American	17	19%	10	14%
Asian / Pacific Islander	12	14%	9	12%
American Indian or Alaska Native			1	1%
Middle Eastern or N. African			0	0%
Decline to state	3	3%	1	2%
Native American or other Pacific Islander	2	2%	0	0%
Other	1	1%	0	0%
Education - highest level completed (2017 n=88; 2018 n=74)				
Did not grad from HS (2017) or some high school (2018)	9	10%	1	1%
HS graduate	12	14%	4	5%
Some college - no degree	12	14%	21	28%
Associates degree	10	11%	5	7%
Bachelor's degree	20	23%	14	19%
Some graduate level - no degree	5	6%	9	12%
Graduate degree	20	23%	20	27%
Family income (2017 n=84; 2018 n=73)				
<\$23,000	14	17%	6	8%
\$23,000-\$46,000	25	30%	18	25%
\$46,001-\$75,000	11	13%	15	21%
\$75,001-\$100,000	16	19%	11	15%
>\$100,000	18	21%	23	32%

¹ [As cited on kidsdata.org](https://kidsdata.org), Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health, National Survey of Children's Health (Sep. 2013).

Table 3. California: Race/ethnicity of Children with Special Health Care Needs: 2011-2012*	
Hispanic/Latino	45.4%
White	33.4%
African American/Black	11.0%
Asian	4.9%
Multiracial/Other	5.4%

*[As cited on kidsdata.org](http://kidsdata.org), Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health, National Survey of Children's Health (Sep. 2013).

Among graduates responding to the survey in 2018, 93% reported at least “some college” education (77% in 2017) with 27% of all graduates reporting a graduate degree (23% in 2017). Income distribution skewed somewhat higher among 2018 graduates with 32% reporting family income over \$100,000 compared to 21% for the same income range in 2017. Still, considerable diversity in family income was represented in 2018 with 33% of graduates reporting family income under \$46,000 (47% in 2017).

The 2018 survey collected new demographic information about the insurance and agency programs that each graduate family uses (Table 4), as well as the types of health and disability challenges faced by graduates' special needs children (Table 5). These data will be added to the program's graduate database and will enable staff to better serve graduates.

Table 4. 2018: Insurance and Agency Programs that Respondent Family Uses (N=73)		
Answer Choices	No. respondents	Percent
Medi-Cal	59	81%
Regional Center	53	73%
Private insurance	39	53%
In-Home Supportive Services (IHSS)	37	51%
California Children's Services (CCS)	24	33%
Supplemental Security Income (SSI)	21	29%
Department of Social Services (DSS)	7	10%
Other (please specify)	7	10%
Early & Periodic Screening, Diagnosis, & Treatment (EPSDT)	5	7%
CHIP / Healthy Families	4	5%
Childcare Resource and Referral	4	5%
Calworks	3	4%
Child Protective Services (CPS)	2	3%
Uninsured	0	0%

Table 5. 2018 Child's Health and Disability Challenges (73 answered, 10 skipped)		
Answer Choices	Responses	Percent
Developmental Disability	32	44%
Autism Spectrum Disorder	29	40%
Speech Language Disorder	28	38%
Intellectual Disability	24	33%
Learning Disability	18	25%
Mental / Behavioral Health	18	25%
ADD / ADHD	17	23%
Orthopedic Impairment	17	23%
Epilepsy / Seizure Disorder	16	22%
Chronic Health Condition	15	21%
Neurological Impairment	13	18%
Visual Impairment	13	18%
Hearing Impairment	11	15%
Down Syndrome	8	11%
Genetic Disorder	8	11%
Other Health Impairment	8	11%
Traumatic Brain Injury	4	5%
Uncertain / Undiagnosed	4	5%
Chromosomal Disorder	3	4%
Other	3	4%
Muscular Dystrophy	1	1%

Another question that was new for the 2018 survey asked graduates if they had had a paying job at any time since completing the training. Sixty-three percent of respondents indicated “yes.” A follow-up question asked about the utility of *Project Leadership* skills in connection with their employment. Six individuals indicated that the skills they acquired directly led to their job and an additional 21 graduates indicated that the skills have assisted them in performing the responsibilities of their position. (Table 6.)

Table 6. 2018: Thinking about your current (or past work since you completed the Project Leadership training, please choose which of the following choices best completes this statement: The skills I learned during the Project Leadership training and my involvement/networking with Project Leadership following the training. . . (n=46)		
Answer Choices	No. respondents	Percent
Directly led me to my job and have assisted me in performing the responsibilities of my position.	6	13%
Have assisted me in performing the responsibilities of my position.	21	46%
Have been helpful in my life, but are not necessarily useful in my work.	18	39%
Have not been useful in either my life or my work.	1	2%

Self-assessment of current use of skills and confidence acquired through training.

The survey asked graduates, “Do you use the skills you obtained in the Project Leadership training including effective communication and partnership. . .

- With health care providers when advocating for your child? (Q5) and
- In your work with committees, boards, decisionmakers, media or in other leadership roles? (Q6)

Results are summarized in Figures 1 and 2, below.

Figure 1. Do you use the skills you obtained in the Project Leadership training, including effective communication and partnership, when advocating for your child? (n=83)

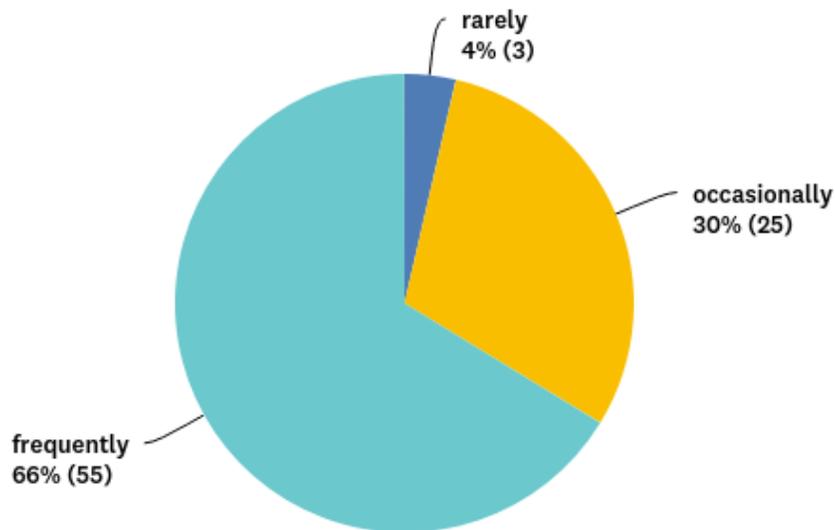
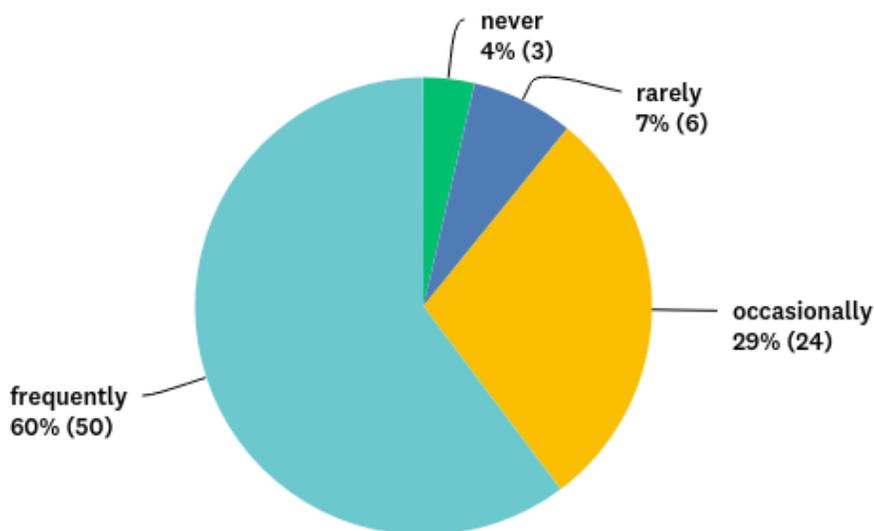


Figure 2. Do you use the skills you obtained in the Project Leadership training, including effective communication and partnership, in your work with committees, boards, decisionmakers, media or in other leadership roles? (n=83)



As seen above, 96% of graduates use their *Project Leadership* acquired skills at least occasionally (66% frequently) when advocating for their child, and 89% used their acquired skills at least occasionally (60% frequently) in leadership roles. As seen in Tables 7 and 8, when compared with results from the 2017 survey, the overall numbers in 2018 of those who have used their skills is similar, although there were more graduates reporting “frequent” use in 2017 in response to both questions.

Table 7. Do you use the skills you obtained in the Project Leadership training, including effective communication and partnership, when advocating for your child? (2017 n=94; 2018 n=83)

	2017		2018	
	No. responses	Percent	No. responses	Percent
Never	0	0%	0	0%
Rarely	3	3%	3	4%
Occasionally	17	18%	25	30%
Frequently	74	79%	55	66%

Table 8. Do you use the skills you obtained in the Project Leadership training, including effective communication and partnership, in your work with committees, boards, decisionmakers, media or in other leadership roles? (2017 n=94; 2018 n=83)

	2017		2018	
	No. responses	Percent	No. responses	Percent
Never	1	1%	3	4%
Rarely	8	9%	6	7%
occasionally	22	23%	24	29%
frequently	63	67%	50	60%

The survey asked graduates to rate their current confidence in some of the specific skills that are part of *Project Leadership* training. Results for 2018 and 2017 appear below in Tables 9 and 10.

Table 9. 2018 results:

Please indicate your level of confidence in the following areas:

	NOT AT ALL CONFIDENT	NOT VERY CONFIDENT	SOMEWHAT CONFIDENT	VERY CONFIDENT	TOTAL	WEIGHTED AVERAGE
A. I am confident that I can participate in policy change discussions with decision-makers.	2% 2	8% 7	43% 36	46% 38	83	3.33
B. I am confident that I can use advocacy tools specific to various issues/advocacy situations.	1% 1	2% 2	32% 26	65% 53	82	3.60
C. I am confident that I can tell my child's story in a way that informs people with decision-making power about why they need to change policies and systems.	0% 0	1% 1	35% 29	64% 53	83	3.63
D. I am confident that the Project Leadership training has prepared me to become an advocate.	0% 0	2% 2	27% 22	71% 59	83	3.69

Table 10. 2017 results:**Please indicate your level of confidence in the following areas:**

	NOT AT ALL CONFIDENT	NOT VERY CONFIDENT	SOMEWHAT CONFIDENT	VERY CONFIDENT	TOTAL	WEIGHTED AVERAGE
A. I am confident that I can participate in policy change discussions with decision-makers.	0% 0	6% 6	41% 38	53% 49	93	3.46
B. I am confident that I can use advocacy tools specific to various issues/advocacy situations.	0% 0	5% 5	23% 21	72% 67	93	3.67
C. I am confident that I can tell my child's story in a way that informs people with decision-making power about why they need to change policies and systems.	0% 0	1% 1	19% 18	80% 75	94	3.79
D. I am confident that the Project Leadership training has prepared me to become an advocate.	0% 0	3% 3	21% 20	76% 71	94	3.72

Overall confidence levels remain high in 2018, however there may be slightly fewer graduates who have rated themselves “very confident” than in the previous year. A number of new groups graduated from the training during the year between the two survey administrations. We compared results between recent graduates (defined as those who graduated one year or less previous to the 2018 survey) to those who graduated more than one year prior to the 2018 survey. The results appear in Table 11, below.

Table 11. 2018 graduates: Comparing recent graduates (“new” n=29) to those who graduated greater than one year before survey (“old” n=54)

Q: Please indicate your level of confidence in the following areas:

	Not at all confident		Not very confident		Somewhat confident		Very confident		Weighted average	
	new	old	new	old	new	old	new	old	new	old
I am confident that I can participate in policy change discussions with decisionmakers.	0%	4%	10%	7%	55%	37%	34%	52%	3.24	3.37
I am confident that I can use advocacy tools specific to various issues/advocacy situations.	0%	2%	0%	4%	38%	28%	62%	66%	3.62	3.58
I am confident that I can tell my child’s story in a way that informs people with decision-making power about why they need to change policies and systems.	0%	0%	0%	2%	45%	30%	55%	69%	3.55	3.67
I am confident that the Project Leadership training has prepared me to become an advocate.	0%	0%	0%	4%	31%	24%	69%	72%	3.69	3.69

While confidence levels are high among both “old” and “new” graduates, it may not be surprising to note that there appear to be fewer “new” graduates indicating “very confident” about their ability to participate in policy change discussion with decisionmakers as well as their ability to tell their child’s story in a way that informs decisionmakers about why they need to change policies and systems. It would make sense that experience in the policy change arena builds confidence, but it is likely that this takes experience and time.

A breakout of “new” and “old” graduates’ self-reported use of *Project Leadership* acquired skills appears in Tables 12 and 13, below, and suggests that both “new” and “old” graduates are actively using their skills, both in advocating for their own children and in leadership positions with groups, although perhaps slightly less frequently for the latter. This may be consistent with the theory that leadership skills in the advanced realms of systems and policy change evolve with time and experience, as graduates’ success and confidence grows.

Table 12. 2018 results: Do you use the skills you obtained in the Project Leadership training, including effective communication and partnership, when advocating for your child? (“new” n=29) to those who graduated greater than one year before survey (“old” n=54)

	new		old	
	No. responses	Percent	No. responses	Percent
Never	0	0%	0	0%
Rarely	3	10%	0	0%
occasionally	6	21%	19	35%
frequently	20	69%	35	65%

Table 13. 2018 results: Do you use the skills you obtained in the Project Leadership training, including effective communication and partnership, in your work with committees, boards, decisionmakers, media or in other leadership roles? (“new” n=29) to those who graduated greater than one year before survey (“old” n=54)

	new		old	
	No. responses	Percent	No. responses	Percent
never	1	3%	2	4%
rarely	2	7%	4	7%
occasionally	10	34%	14	26%
frequently	16	55%	34	63%

Graduate contact with legislators and media.

Graduates were asked about their contacts with legislators and other elected officials, as well as their contacts with media. Asked if they had communicated with any legislator or elected official during the last year, 58% of graduates responded “yes.” Of those who did make contact, 82% reported having done so on multiple occasions. Table 14, below, shows frequency of contact and also shows the mode of contact used by graduates. Email contact was reported by many (70% of those who contacted legislators), and a high number of in-person visits were also reported (57% of those who had contacts with legislators). It is difficult to compare 2018 results to 2017 results because the 2018 question was confined to graduates’ activity “during the last year” whereas the 2017 survey sought information about graduates’ experience “since graduation.” Still, the results appear very similar.

Table 14. 2018 Results: Graduates’ contact with legislators in previous year		
(In last year), communicated with any legislator or elected official (n=80)		
	No. responses	Percent
Yes	47	58%
No	33	41%
(In last year) number of times communicated (n=46)		
1 time	8	17%
2 times	11	24%
3-5 times	19	41%
6 or more times	8	17%
(In last year) check all ways communicated (n=47)		
Email	33	70%
Telephone	17	36%
Letter or postcard	9	19%
Social media	20	43%
In-person visit	27	57%
Other (please specify)	1	2%

The survey also requested information about contacts with media was also requested, and 17% of graduates reported some form of media contact. Results appear in Table 15. Again, although 2017 and 2018 survey results are not directly comparable, they appear to be very similar. For instance, in 2017, 11% of graduates reported having provided interviews with the media whereas in in 2018, 12% of graduates reported about interviews.

Table 15. 2018 Results: Have you interacted with the media during the last year? Please check all the answers that apply. (n=81)		
	No. responses	Percent
No.	67	83%
Yes, I've written letters to the editor or similar.	1	1%
Yes, I've participated in a press conference.	0	0%
Yes, I've provided one or more interviews to the media.	10	12%
Other (please specify)	8	10%

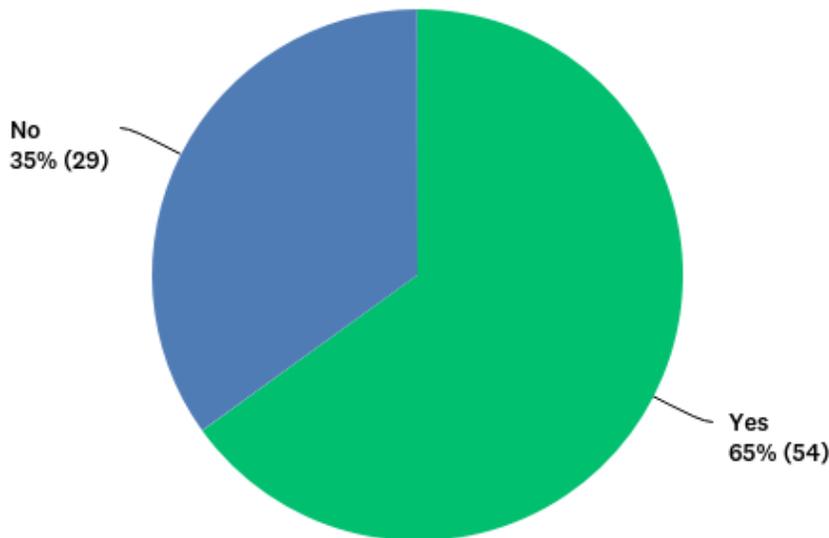
The survey also collected information about graduate participation in other advocacy related activities. Results are reported in Table 16.

Table 16. 2018 Results: During the last year, have you participated in any of the following advocacy / leadership activities? Please check all that apply. (n=78)		
	No. responses	Percent
Speaking or presenting individually or as part of a panel.	33	42%
Participating in rallies.	16	21%
Partnering with providers to advocate for children with special health care needs.	23	29%
Providing testimony / giving public comment.	21	27%
None of these advocacy activities	23	29%
Other (please specify)	8	10%

Membership on committees, boards, councils, stakeholder groups, taskforces and other groups.

Project Leadership training prepares graduates to engage with decisionmaking and advocacy groups in many ways. Ongoing mentorship also supports graduates looking for participation opportunities. The survey asked a number of questions about graduates' membership in groups. As seen in Figure 3, 65% reported that they had been members of one or more groups during the previous year.

Figure 3. 2018 Results: In the last year, have you been a member of any committee, board, council, stakeholder group, taskforce, or any other group focused on children with special health care needs/disabilities? (n=83)



The survey asked those who said they had participated as members in groups to classify the types of groups they'd participated in. Of those who responded (n=52):

- 46% said they'd been part of a group that focused on health/mental health (categories most frequently checked included California Children's Services, hospital based, and Medi-Cal focused groups);
- 50% said they'd been part of a developmental disabilities group (categories most frequently checked included Regional Center and State Council on Developmental Disabilities);
- 46% said they'd been part of an education focused groups* (categories most frequently checked included Community Advisory Committee, "other," and School Site Council);
- 33% said they'd been part of one or more "other" groups that are not health/mental health, developmental disabilities or education focused.

**When FVCA reviewed open-ended responses, they found several explanations that suggested graduates may have interpreted this question as seeking the setting of the group because there were health issues involved in an education setting.*

The survey requested information about each group that graduates had participated in over the previous year, including each group’s specific name. Graduates were asked questions about that experience, including:

- Whether the graduate was still involved;
- If they were not still involved, the reasons they had departed;
- The level of the group (local, regional, state, national) and the domain the group belongs to (health/mental health, developmental disabilities, education, other);
- The graduate’s participation experience (e.g. were they welcomed by the group, was it a satisfying experience);
- The extent of policy change.

For graduates who had participated in more than one group over the previous year, the survey provided the opportunity to answer questions and report on up to four groups. Of the 54 graduates who reported having been a member of group over the previous year, 53 graduates named and described a total of 109 groups.

Table 17. 2018 Results: Participation in groups over previous year: Number of groups named by graduates (83 graduates; 53 grads named 109 groups)

	# of graduates	% of graduates
Number of groups described		
0	30	35%
1	19	23%
2	20	24%
3	7	8%
4	6	7%
5 or more	1	1%

Most of the groups named and assessed by graduates were described as “local” or “regional” with fewer groups described as operating at the “state” level and fewer still described as “national.” (Table 18.)

Table 18. 2018 Results: At what level does [group] function most of the time? (53 graduates assessed 107 groups participated in over one year)

	# of groups	% of groups
Local (neighborhood, community, city)	48	45%
Regional	32	30%
State	18	17%
National	7	7%
Other	2	2%

The domain of the groups described by graduates was varied, with “education related” the most frequently named area. A very significant participation was also reported in both “developmental disabilities” groups and “health/mental health” groups. Open-ended answers suggest that a number of graduates may have chosen “education related” in this multiple choice question because education was the setting for the group, even if health aspects were involved. (Table 19.)

Table 19. Please check which of the following categories best describes [group]. (53 graduates assessed 105 groups they participated in over one year)

	# of groups	% of groups
Health / mental health related.	24	23%
Developmental disabilities related.	28	27%
Education related.	37	35%
Other (none of above).	16	15%

Systems and policy change affecting CSHCN is a major goal of *Project Leadership*, so the program continues to be interested in tracking successful change. Group participants reported seeing policy or systems change improvement in 31% of the groups described by graduates in the 2018 survey. In an additional 36% of groups, there had not yet been change, but such changes were under consideration. (Table 20.) Graduates were asked to describe systems and policy changes in an open-ended question and these narrative answers are included in the Appendix to this report.

Table 20. 2018 Results: Was there any positive policy or systems change during your time serving on [group]? (53 graduates assessed 107 groups they participated in over one year)

	# of groups	% of groups
Yes, there was a policy or systems change or improvement.	33	31%
No, but policy or systems changes are under consideration.	36	36%
No. There has been no change for now, but decision-makers have indicated greater understanding and change may be possible in the future.	28	26%
No. There’s been no change and no apparent impact.	10	9%

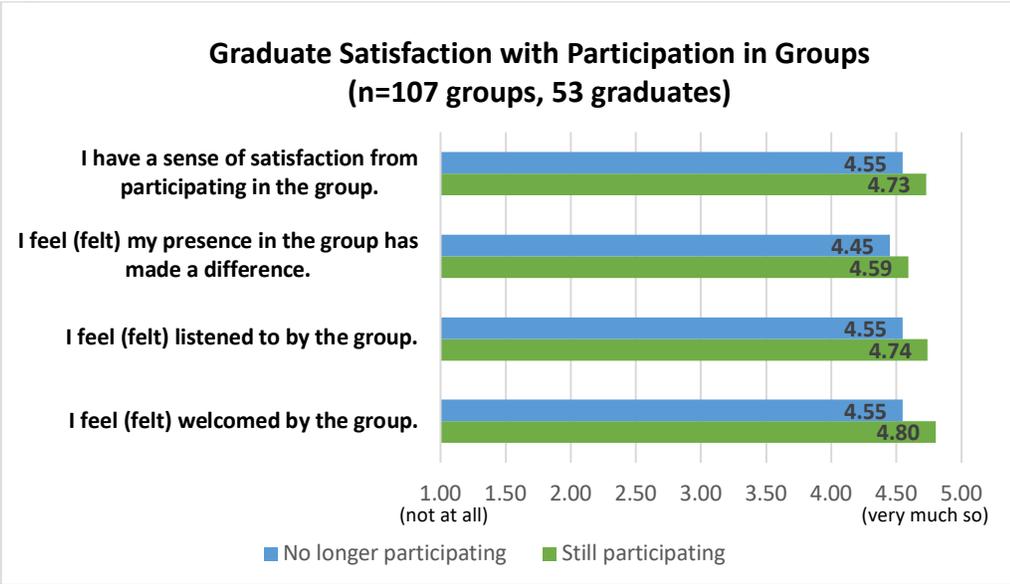
Participants reported that they continue to participate in all but 10 of the groups described. Asked why they no longer participate in those groups, respondents reported that 4 groups are no longer operating, for 3 groups the graduate’s term ended, and for 2 situations graduates chose to stop participating for other reasons. For one group, there is no information provided. “Other reasons” expressed were difficulty with the location and time of meetings and, in one case, disagreement about how the group was run.

Graduates reported on their experiences in working with groups, including the extent to which they felt welcomed, listened to, that their presence made a difference, and their overall level of satisfaction from participating. Asked to rate their agreement on a scale of 1-5, with 1 indicating “not at all” and 5 signifying “very much so,” average satisfaction scores were high and ranged from 4.58 to 4.78 on the 5 point scale. (Table 21.)

Table 21. 2018 Results: Thinking about your work with [group name], please respond to each statement about your participation as a member of the group. [1-5 rating with 1=“not at all” and 5=“very much so”]		
	# of groups rated	Average satisfaction score
I feel (felt) welcomed by the group.	107	4.78
I feel (felt) listened to by the group.	106	4.73
I feel (felt) my presence in the group has made a difference.	107	4.58
I have a sense of satisfaction from participating in the group.	107	4.71

When comparing groups where graduates are still participating to groups where graduates were no longer participating, scores were only slightly lower for the groups where graduates no longer participate. (Figure 4.)

Figure 4.



Among recent graduates from *Project Leadership*, 69% reported membership in groups during the previous year, so there is no indication that their participation is lagging behind that of those who graduated more than a year ago.

Graduates were asked to check all of the types of groups that they are not currently participating in but are considering working with in the near future.

- 45% checked health/mental health related groups;
- 51% checked development disability related groups;
- 39% checked education related groups; and
- 14% checked “other” groups, not related to the above.

Asked if they wished assistance from FVCA (getting connected to a group or help with the application process), 35% of graduates requested assistance in the form of a call or email while 65% indicated that they were “all set.” Requests for assistance from FVCA *Project Leadership* staff appear to be increasing. In the 2017 survey, only 29% of graduates requested assistance with joining future groups.

Post-graduation mentoring and support services.

An important component of the *Project Leadership* program is ongoing mentoring and support of graduates seeking to use their *Project Leadership* training. The survey asked graduates about their participation and satisfaction with support services offered by FVCA. Of the 83 graduates responding to the 2018 survey, 79 provided information about their participation in various categories of mentorship/support as summarized in Table 22, which also provides data from the 2017 survey for comparison purposes. While the types of services and description of them evolved from the 2017 to 2018 surveys, participation rates appear to be very similar between the two years.

Table 22. Participation in FVCA offered support. (2017 n=90) (2018 n=79)				
	2017		2018	
Note: where different options were offered in the 2017 and 2018 surveys they are shown below	Have not participated	Have participated	Have not participated	Have participated
*(2017) Project Leadership Online Advocacy Group (Social Media). Note: This is now a Facebook group and in the past was a Google group).	42%	58%		
*(2018) Project Leadership Online Advocacy Group			45%	55%
*(2017) Webinars / conference calls with Project Leadership Manager, Allison Gray.	52%	48%		
*(2018) Conference calls with Project Leadership staff			59%	41%
*(2018) Webinars with Family Voices of California / Project Leadership Staff			47%	53%
*(2017) Email / phone contacts, individually, with Project Leadership Manager, Allison Gray.	40%	60%		
*(2018) Email / phone contacts, individually with Family Voices of California / Project Leadership Staff			32%	68%
*Email / phone contacts with other graduates.	33%	67%	41%	59%
*Annual in-person gatherings (one in Northern CA and one in Southern CA).	42%	58%	44%	56%
*Family Voice of California Health Summit and Legislative Day in Sacramento.	57%	43%	54%	46%
*(2017) Special events, such as Op/Ed Writing Workshop with Daniel Weintraub.	75%	25%		
*(2018) Other – please specify.			81%	19%

Of those who participated in each activity, ratings of the usefulness of each type of support were provided. An average weighted score was calculated for each, with “1” assigned to “not useful at all,” “2” to “not very useful,” “3” to “somewhat useful” and “4” to “very useful.” As seen in Table 23, below, all activities were highly valued by graduates, with weighted scores for activities ranging between 3.53 (conference calls) and 3.75 (FVCA Health Summit and Legislative Day and individual email and phone contacts).

Table 23. 2018 Results: Please rate the usefulness of the following types of support opportunities offered to Project Leadership graduates by Family Voices of California: (ratings by those who have participated)

	Not useful at all	Not very useful	Somewhat useful	Very useful	Weighted average
*Project Leadership Online Advocacy Group (Facebook) n=43	0%	7%	35%	58%	3.51
*Conference calls with PL staff n=32	0%	6%	34%	59%	3.53
*Webinars with FVCA / PL n=41	0%	10%	27%	63%	3.54
*Email/phone contacts, individually, with FVCA / PL staff n=53	0%	4%	17%	79%	3.75
* Email / phone contacts with other graduates. n=44	0%	9%	18%	73%	3.64
*Annual in-person gatherings (one in Northern CA & one in Southern CA)n=43	0%	7%	21%	72%	3.65
* FVCA Health Summit and Legislative Day in Sacramento. n=36	0%	6%	14%	81%	3.75
*Other (please specify) n=6	0%	17%	17%	67%	3.50

Satisfaction scores appear roughly comparable to those reported on the 2017 graduate survey (See prior year’s report.) When “new” graduates were analyzed separately (2018), their weighted average satisfaction scores ranged from a low of 3.73 (webinars) to a high of 3.91 (annual in-person gatherings) on a 4-point scale.

Analysis of surveys submitted by Spanish-speaking graduates.

Project Leadership training is delivered to some graduate groups in Spanish. The graduate survey was translated into Spanish and offered to those graduates in 2017 and 2018. The results reported above include all surveys responded to in Spanish as well as English. There were eight surveys completed in Spanish in 2018 and 14 surveys completed in Spanish in 2017. We separately analyzed Spanish surveys to identify potential differences that could be important for the program as it moves into the future.

- Regarding use of *Project Leadership* skills, both 2017 and 2018 Spanish responses indicate that Spanish speaking graduates are using their acquired skills.
 - In advocating for the graduate's child:
 - For 2017, 86% reported frequent use and an additional 14% reported occasional use (0 said "rare" or "never").
 - For 2018, 50% reported frequent use and an additional 50% reported occasional use (0 said "rare" or "never").
 - In work with committees, boards, decisionmakers, media or other leadership roles, self-reported use of *Project Leadership* skills was lower than among English speakers, likely reflecting language barriers and more limited opportunities:
 - For 2017, 57% reported frequent use and an additional 36% reported occasional use (7% said "rare" and 0 said "never").
 - For 2018, 50% reported frequent use and an additional 25% reported occasional use (14% said "rare" and 14% said "never").
 - Regarding confidence levels (see Table 8, above):
 - For 2017 survey, average scores were slightly lower than scores for English speaking graduates in three categories, but exceeded those of English speakers in one category (confident I can tell my child's story. .)
 - For 2018, average scores met or exceeded scores for English speaking graduates for all four confidence statements.
 - Reporting of membership on committees, boards, and similar organizations, however, was lower among Spanish speakers in 2018. Again, this may be due to language barriers / lack of opportunity.
 - For 2017, this was not so, as 71% indicated that they had participated. The question, however, was changed and clarified in 2018 to make it clear the question sought information about membership on committees, boards, etc, rather than other types of participation. It is also possible that this difference is related to the level and type of ongoing support from Spanish speaking trainers.
 - For 2018, only 38% of Spanish speaking graduates indicated that they had been a member of a group during the previous year. The three graduates who had done so reported their experiences with five groups.
 - Spanish speakers reported a number of plans to join groups in the future and 57% requested assistance from staff in that endeavor. That percentage is greater than that of English speaking graduates.
 - Contact with legislators was lower among Spanish speakers than English speakers in both 2017 (36% of Spanish speakers initiated contact) and 2018 (14% of Spanish speakers had contact).

- Satisfaction with FVCA provided mentoring and support services was high.
 - For 2017, average usefulness scores were higher, overall, than those for English speakers, with ratings of usefulness exceeding those of English speakers in all categories except the annual meetings (Sp. =3.33) and the FVCA Health Summit and Legislative Day (Sp = 3.75).
 - For 2018, average usefulness scores continued to surpass those of English speakers except for annual in-person gatherings, and in that case, still was 3.5 on a 4.0 score.

Graduates recommendation of the training.

Graduates continue to state that they are likely to recommend the training to another parent of a child with special health care needs, with 82% stating that they are “very likely” to make such a recommendation.

Table 24. How likely are you to recommend the Project Leadership training to another parent of a child with special health care needs / disabilities? (2017 n=90; 2018 n=76)

	2017	2018
Very likely	81% (73)	82% (62)
Likely	17% (15)	17% (13)
Unlikely	0% (0)	1% (1)
Very unlikely	2% (2)	0% (0)

PROJECT LEADERSHIP SKILLS IN ACTION.

While the survey provided opportunities for graduates to write narrative descriptions of their activities in the field (narrative answers are incorporated in the Appendices to this report), the answers were generally brief. *Project Leadership* staff, together with the evaluation consultant determined that interviews of several of the survey respondents could provide a more vivid picture of the types of projects undertaken by graduates and how the ongoing support of FVCA *Project Leadership* plays a role for graduates. The evaluator pulled specific data about group work described by graduates from the surveys and FVCA reviewed those data and suggested names of graduates who might be interviewed for this purpose. The evaluator interviewed three graduates and excerpts from those interviews appear below.

Alisa Rosillo.

“It is important that *Project Leadership* teaches people to advocate in a positive light so that it doesn’t make us the crazy people. It legitimizes our cry for equity.”

Alisa is the mother of two sons with complex needs. Her 20-year-old son has cerebral palsy and her 18-year-old has quadriplegia and a ventilator, and Down syndrome. Although she notes that her home situation makes it difficult for her to be a part of committees, she considers herself “a bit of a rogue warrior.” “I find things that interest me, and then I run with it.”

Her initial foray into advocacy began when she and a friend entered a contest “It Oughta Be a Law,” sponsored by her state assemblymember. Alisa was frustrated to find disabled parking spaces frequently inaccessible. Working with then Assemblymember Mark DeSaulnier, she succeeded in advocating for passage of Assembly Bill (AB) 1531 which became a California law in 2007. The law resulted in better marking with blue and white of the aisles, allowing easier entry and exit for wheelchairs from cars in disabled parking. The bill also increased fines for violators.

Alisa was attracted to the *Project Leadership* training which she completed in 2014. “I used it as a catalyst for my second bill which was AB 662 for adult changing facilities in California.” She knew she was starting from scratch this time around in trying to change the law to require adult changing tables when building new facilities. “You are asking people to give up space to make the restroom,” she said. Sponsored by Alisa’s Assemblymember, Susan Bonilla, AB 662 requires that all “commercial places of public amusement” built after January 1, 2020 include and maintain at least one adult changing station for people with disabilities. Businesses that are renovated after January 1, 2025 must also upgrade their property to include an adult changing station. The bill passed and was signed into law in 2015.

“*Project Leadership* gave me the opportunity to say, well I’m going to present this in a way that it’s going to fly. Who’s my audience? How am I going to approach this? Who are we leaving out of the equation? It really made me think about all of the pros and cons that you are going to face along the way. That was not something I dealt with the first time around.”

“I had to get the statistics to support it, and it was difficult because you are talking about creating a demographic of people. This is a hidden population – they are people who don’t go out because they can’t go to the bathroom. . . And that was part of how I presented this to the Appropriations Committee. I showed up with my son. And I said, ‘Here I am today. I’m guessing that when you got up today and had your cup of coffee you went to the bathroom before you drove to work. And you got yourself situated, and then you went to the bathroom again before we came in here and sat down. And now that I’ve talked about going to the bathroom a couple of times, you’re probably thinking about going to the bathroom again! But, the reality of it is that my son got changed when we left Concord 90 minutes ago. And then we got done parking, and then we waited to speak. And then when we get done speaking, we’re going to have to drive another 90 minutes, and that’s the next time he’s going to go to the bathroom. And where is the dignity in that? And what if that was you, or your grandmother, or your brother who served in Iraq?’”

Asked how *Project Leadership* has supported her in her advocacy, Alisa explained, “it helps me to be more refined in how I do things. Because when you are just kind of a mom, you’re running on emotion and personal need. *Project Leadership* helps you to think a little more globally which helps more than just your child. That’s a really hard mindset when parents are sort of in that fight or flight mode – to just hang on to the services that they have or need. . . Thinking globally, that was the one thing that the class really helped me do.”

Alisa commented, as well, on the ongoing, post-graduation support provided by *Project Leadership*, “It is irreplaceable. . . You build a network and it is so critical. Your life is touched by so many people from so many demographics that deal with so many agencies and districts, and it helps you advocate when you find out that everybody is doing something or nobody is doing something. You find out what you’re up against on a larger scale. It gives you this network of people and resources and knowledge.”

“Each one of us has a network within our network. We are a group of people whose ear is to the ground. . . it allows us to work collectively for the interest of all of our people.”

“It is so critical for those of us out there who are trained to bring people into the fold. It is our job to train people who don’t want to be educated and to do it in a way that is not met with resistance.”

Dena Davis.

Dena had recently moved back to California from Maine in 2015 and was navigating the health care system on behalf of her son. There were “bumps in the road” both at school and with getting authorization that his condition qualified for California Children’s Services (CCS). Dena attended a parent support group at Alpha Resource Center in Santa Barbara, and when she expressed an interest in advocacy, was referred to the *Project Leadership* training. She finished the training in early 2017, and shortly after graduation, ran for and was elected President of the PTA at her son’s school.

“One thing I learned at *Project Leadership* was about building relationships and working collaboratively. So that was also my motivation - to put my money where my mouth was and give back to the school and represent all students and not just be advocating for my son and his friends. I kind of took a broader approach and I think it gave me more credibility when it comes to advocating for specific things.”

As PTA President, Dena succeeded in leading a number of changes, including:

- Changing the school's "jog-a-thon" to a "move-a-thon" and changing the flyers to include images of kids with different abilities;
- Persuading others to hold the "move-a-thon" on a surface that would be accessible to children with wheelchairs, walkers, and orthotics rather than the grass field favored by many, but full of gopher holes that made it inaccessible;
- Making sure that special education teachers and speech therapists receive a classroom stipend. "The PTA provides this and it is intended for classroom teachers. The speech and special education teachers are working with smaller groups, but I made sure that they would get it. That has been really helpful for them; it has helped them get adaptive seating and supplies for the sensory room."
- Working with a parent advisory committee to request and obtain an adaptive swing on the playground. The principal paid for it from a fund. "I keep meaning to write a letter to the district about what that one swing means. It also means something in our community, too. Every time people drive by that, they see this is an inclusive school. These tiny little changes can affect the system."

Dena has also been active in the health care arena, serving on the local Medi-Cal health plan (CenCal) Whole Child Model Family Advisory Committee. She was referred to participate by Alpha Resource Center because of her training with *Project Leadership*. The Committee met frequently during her county's transition from traditional California Children's Services to the Whole Child Model. As a member, she gave input about forthcoming communications to families affected by the transition.

CenCal, the Medi-Cal health plan that was absorbing new responsibilities during the transition, also invited Dena and her son to speak to their whole staff, including information processing and billing employees who don't normally interact with the clients they serve. "So, for them to hear who they are serving was pretty powerful," Dena said. Dena believes the Whole Child Model transition has proceeded smoothly in her county, and she continues to serve on the Committee.

Concerning the benefits of the training, Dena observed, "Some of my first emails [before the training] were pretty 'mama bear.' I learned about the collaborative process. With *Project Leadership*, I learned about doing your research first – get all your facts. Learn the history. And the other thing was, you don't need to go it alone. You can go as a group. So, instead of writing a snarky email about why isn't there an adaptive swing, I went to the CPAC [committee] first."

Dena values the ongoing support provided by FVCA *Project Leadership* staff, citing emails that keep graduates up to date about what is happening statewide and participation opportunities. "I've learned at the Health Summit and trainings on social media how to interact with and stay engaged with all of our people in government, and also to recognize them and thank them when they are passing legislation that benefits children with special health care needs." Working with her local Family Resource Center, she's met with a county supervisor and state representatives/staff at their local offices. When her local congressional representative came to a Special Olympics event, she made sure to say thank you to him for being there.

Alison Beier.

“With Family Voices [*Project Leadership*] it was like I was walking down this hallway at the hospital. And Family Voices [said], ‘here, let me show you this door.’ And then they just kicked it open, and I saw this unending world in front of me - - this whole pool of possibility.”

Alison’s son, Evan, has had 60 surgeries over his lifetime and has spent half of his young life in the hospital. Alison became involved with the parent advisory committee at UCLA Mattel Children’s Hospital where Evan received care and became inspired to take her advocacy to the next level. Alison graduated from the Eastern Los Angeles Family Resource Center’s *Project Leadership* session in 2016. Later that year she became chair of the UCLA Mattel Children’s Hospital Parent Advisory Council. She has now presented about her advocacy experiences and success with system change at conferences, both within her hospital and beyond. For example, she’s spoken at a national conference of emergency room nurses together with a registered nurse colleague. “They had never had a patient representative speak before.”

“You get really good at telling your story. *Project Leadership* puts parameters on it. They give you a lot of work – on the elevator speech versus the three-minute speech. That’s where I really learned to ask the questions, like who is my audience and how do they listen to me? You can’t joke to a room full of emergency nurses – they don’t get the same humor!” Alison gets to tell her story at the hospital’s forum for nurses, care partners, and even administrators, once or twice per month and also speaks to new residents as they “on-board” at the hospital. “That’s a really beautiful thing that we get to do. So right from the beginning we’re talking about collaboration and patient-centered care and using our voice in that way.”

Alison speaks passionately about the value of her *Project Leadership* training, and about her ongoing relationship with and support from FVCA’s *Project Leadership*. “*Project Leadership* educated me and empowered me to be able to delve into other areas. I got that polishing, that confidence, that knowledge that you don’t have to just exist in a hospital, you can take part in legislation.” She has been to the Health Summit for three years. “It’s not just me. When you go to Sacramento, you bring the whole family. And so my son starts to see how I advocate on behalf of him. And then he gets really polished.”

Alison said it was her *Project Leadership* training and her experience at the FVCA Health Summit that caused UCLA to ask her to advocate with the Children’s Hospital Association in Washington, DC. “Because we had done the work already and had practiced, we were so efficient. . . Nancy Pelosi called me and my son ‘eloquent.’” They were able to advocate in support of the ACE Kids Act, for the continuation of Children’s Health Insurance Program and against repeal of the Affordable Care Act.

Alison’s passion for advocacy has evolved even further, as she recently accepted a job as a special needs advocate through Autism Society of Los Angeles, working exclusively with African American and Latino families at the West Side Regional Center. “Making the quality of life for these people better - - that’s what I get to do now because of *Project Leadership* and what I’ve learned there. It is very fulfilling. Now I want to do the train-the-trainer training. *Project Leadership* is something I believe so wholeheartedly in that I push it as much as I can to any advocate parent that wants to do better and learn more.”

Regarding the ongoing network, Alison stated, “It’s not just the four Saturdays that I spent. It’s the continued relationship. . . When you do this kind of work, the peer-to-peer network means so much. If I need a resource for anything, I can reach out to them. . . they are always there. They believe in you. There’s nothing I wouldn’t take on because I know I have their support.”

Conclusions and recommendations.

An evaluation of the initial implementation of *Project Leadership* with the first two graduating classes in 2013-14 concluded, “by every measure, *Project Leadership* successfully met its goals.” It noted improvements from pre-training to post-training and suggested that longer term evaluation could provide even stronger evidence of effectiveness. The inclusion of the same items in the current survey, as well as in a similar graduate survey fielded in 2017, further strengthens the conclusion that participants continue to use and have confidence in the skills learned during the training. The ongoing support and mentorship of graduates by FVCA, however, is very likely playing a strong role in maintenance of advocacy activity by graduates. Graduates participate in support activities, and their ratings of FVCA’s range of offerings demonstrate the value that they place on this ongoing support.

New demographic questions added for the 2018 survey should enhance FVCA’s ability to serve graduates by pinpointing opportunities most relevant to graduates’ needs and connecting graduates to each other, as appropriate.

Based on the data collected in graduate surveys from 2017 and 2018, as well as conversations with staff, the following recommendations are posed for consideration by FVCA leadership and its supporters.

1. A primary recommendation is the continuation of the training and FVCA’s strong program of support to graduates. Significant numbers of graduates participated in FVCA-provided graduate support activities and these activities are highly valued by graduates. While all opportunities were highly rated, individual communication with FVCA staff via telephone and email as well as the FVCA Health Summit and Legislative Day scored an average of 3.75 on a 4-point scale. As seen in more detail in the graduate interviews, the support network provides a source of help and confidence for graduates as they expand their advocacy experience. They take on issues and processes that may be unknown to them, but they move forward anyway with the confidence that there is a place to call for information and support. As articulated by graduate Alison Beier, “. . . you feel so alone because don’t know the path, but you know there’s probably an answer. You just don’t know how to get there. [FVCA staff] are always there. They believe in you. There’s nothing I won’t take on because I know I have their support.”
2. Continue to develop ways to support underrepresented families, including those who are not native English speakers. Although there were only eight surveys submitted in Spanish in 2018, only three of the eight had participated as members of groups during the previous year, but 6 of the 8 expressed plans to join groups in the future and 57% requested support from FVCA in that process. Contact with legislators was lower among Spanish speakers, likely due to fewer opportunities and communication challenges.

3. Find ways to leverage and expand FVCA's support network. Staff has expressed an interest in identifying ways to support and activate trainers to partner with FVCA in support of graduates. While FVCA support services do allow staff to get to know new graduates, it is the local trainers who are most familiar with new graduates and in the best position to mentor them. This could prove particularly valuable to graduates with less experience and confidence as they seek to identify local opportunities and move into advocacy roles. From the 2018 data we can see that graduates choose opportunities close to them. As seen above, 45% of the groups graduates were members of during the previous year were "local" and 30% were "regional." If local trainers participate in post-training mentorship, families from underrepresented areas, Spanish speakers, and students with little or no pre-*Project Leadership* experience may have a better chance to put their skills into action.
4. Continue evaluation efforts. While the positive feedback from the 2017 and 2018 graduate surveys might suggest that the program "works" and program time and resources should therefore be focused somewhere other than evaluation, it is important to continue to pursue ongoing evaluation. This is particularly true as the program has evolved to a "train-the-trainer" model. Staff report that they already actively survey trainers. This should continue to inform the program and provide feedback about how to enhance the training of trainers and support program graduates and trainers. Staff also report their intention to conduct an "impact" survey with organizations where graduates are participating. The purpose is to assess organizational perception of the value of family participation and to collect information about changes in systems and policies. This should prove to be a valuable process with the potential to demonstrate the program's value beyond the perception of graduates. While the program does not currently plan to survey graduates, it may prove valuable to consider on-line surveys that continue to collect feedback about support and mentorship, particularly if local mentorship becomes an added aspect of the program. This could also assist in identifying which organizations to survey with the planned impact survey.

The graduate survey results from 2017 and 2018, taken together, demonstrate graduate participation in a wide range of leadership groups, legislative issues, and advocacy behaviors. This is certainly remarkable given the considerable demands faced by families of children with special healthcare needs / disabilities. The continued reach of the program to a diverse audience of parents helps assure that a good representation of California's families of children with special healthcare needs / disabilities will provide strong voices as policy and systems changes are considered.

Appendix A

Project Leadership: 2018 Results From a Survey of Graduates.

June 21, 2019

Narrative responses from 2018 Project Leadership Survey of Graduates:

Q 9. Other type of group that is not health/mental health, developmental disabilities, or education related group. Please specify.	
1	Teache for special Education
2	Our kids can
3	I am a member of the newly formed Disabilities Awareness Committee at the Golden Empire Council which supports over 15,000 Boy Scouts in Northern California.
4	Epilepsy Foundation of Greater Los Angeles, Teens Speak Up
5	C.A.P.C. Child abuse prevention Committee
6	Developmental Disabilities - Mental Health Services Act - Advisory Committee
7	OAH's SE Stakeholders' Advisory Committee
8	San Diego autism society
9	CPAD, IRB member for Easter Seal
10	In Home Supportive Services Advisory Committee
11	PTA
12	PTA
13	Fair Hearings against Regional Center
14	APIDC Statewide Conference Planning Committee
15	IHSS Advisory Committee
16	I am a parent rep for LCAP for Whittier Union HS District, I am often called upon for parent (emotional) engagement on a volunteer basis with East Whittier City SD
17	Northern CA /East Bay Learning Disabilities Association

Names of groups that graduates have joined:

Q10. Please provide the name of the group that you have been the most active with during the past year. Also includes additional names from Q's 22, 34, 46, 58.

1	Discapacidades de desarrollo
2	Grupos de apoyo en Supportfamily
3	Consejo de sitio escolar
4	Go Bananas
5	participated in student with physical challenges events
6	Kids can
7	CCS Parent Health Liaison-Contra Costa County
8	State Council on Developmental Disabilities - San Diego, Imperial Counties
9	CPAD
10	Family Voices of California Advisory Council
11	Golden Empire Council -Boy Scouts of America
12	CCS Advisory committee
13	Foothill school site counsel
14	UCSF Benioff
15	Transforming Research as Usual- Community Advisory Board
16	Epilepsy Foundation
17	Self determination advisory committee
18	Solano local child care planning council
19	Children's Hospital Foundation
20	Children's Regional Integrated Service Systems Council
21	CenCal CCS transition
22	Mchap
23	Down Syndrome Assoc. of Santa Barbara County
24	SCDD
25	Self Determination Advisory Committee - GGRC
26	Specia lNeeds Advisory Council
27	Dis. Rights CA
28	C.A.P.C. Child abuse prevention Committee
29	Developmental Disabilities - Mental Health Services Act - Advisory Committee - Project Goal - Establishment of a service model for Early Childhood Infant Mental Health Prevention and Early Intervention (PEI) services to children with mild to moderate social and emotional challenges as well as evaluate the effects of system changes at the regional center operations and early intervention partners level to provide increased awareness and primary intervention for families, including those headed by an individual with a disability to support the healthy social/emotional development of children involved in the Early Start program.
30	Unidad y Fuerza, Programa Educativo para Padres de Bellflower, Tichenor
31	OAH's SE Stakeholders' Advisory Committee
32	Parent Support Liaison/promotora
33	CPAD
34	In Home Supportive Services Advisory Committee
35	Self Determination Advisory Committee
36	Monroe Elementary PTA
37	Childrens Hospital Oakland, Family Advisory Council
38	SANKOFA-UCDavis Mind Institute (Advisory Committee)
39	Golden Gate Regional Center
40	MVES School Site Council

Names of groups that graduates have joined:

Q10. Please provide the name of the group that you have been the most active with during the past year. Also includes additional names from Q's 22, 34, 46, 58.

41	I work for RCOC and I'm part of a collaborative via Cal-Optima.
42	Intercoordinating Council for Infants and Toddlers (ICC) in Arizona
43	Community Health Alliance Advisory Committee
45	Educate Advocate and Empower Family California
46	WACSEP CAC, Vice Chair
47	HUB City Autism Network Parent Volunteer Advisory committee
48	Cac
49	UCLA Mattel Childrens' Hospital Parent Advisory Council
50	Transition Task Force of DDC of Contra Costa County
51	PTA
52	CAC
53	CAC Leadership Collaborative
54	Grupo de apoyo en el hospital general de potrero para personas con diabetes
55	Recursos de la clinica de raza
56	MVUSD SEPAC
57	4ca
58	George Mark Children's House
59	Involved Exceptional Parents Day
60	DDS Stakeholder meeting/group
61	Caltash
62	Advisory committee
63	The Mamahood Special Needs Support Group
64	Community Advisory Committee for Special Education
65	Parents empowering parents
66	West Contra Costa Special Education
67	Help Me Grow Advisory Committee (Contra Cost County)
68	Special need PTA and aca
69	Santa Barbara Unified School District Staff Special Education Parent Advisory Committee
70	CHADD
71	Social Justice Steering Committee - Congregation Rodef Sholom
72	School Site Council
73	Juvenile Justice Commissioner Chairperson
74	CA-LEND, interdisciplinary and collaborative collective of researchers, clinicians, and educators from diverse cultural backgrounds
75	San Diego autism society
76	IRB member of Easter Seal
77	Educate Advocate
78	SCDD Regional Advisory Committee Meeting
79	CenCal Whole Child Family Advisory Committee
80	PTA
81	MVES PTO
82	Special Education Parent Council - Gilbert Public Schools - Gilbert, AZ
83	Person-and Family- Centered Care (PFCC) Committee
84	Wsa
85	East Bay Employment Task Force of the DDC
86	SBDM
87	Coalition for Students with Disabilities

Names of groups that graduates have joined:

Q10. Please provide the name of the group that you have been the most active with during the past year. Also includes additional names from Q's 22, 34, 46, 58.

88	Coalition for students with disabilities
89	Community Advisory Board for Mental Health
90	Parent Resource Group (GMCH)
91	SBUSD Transition Committee
92	Overland Elementary School Site Council
93	California Concerned Parents Association
94	Consumer Self-Advocacy Group
95	March for Our Lives
96	HEAL (Healthy eating active living)
97	Arizona's Raising Special Kids - Parent Leader
98	CCS Workgroup
99	Reddit/disability
100	SSC
101	CHAIN (Create Hope Access Independence Now)
102	Family Advisory Committee (UCSF Benioff CHO)
103	La Colina Jr High PTSA
104	The McCormick Center for Early Childhood Leadership
105	Justice In Name Of
106	Parent Rep on the LCAP for WUHSD
107	Support for families of children with disabilities
108	Northern CA/East Bay LDA
109	Hispanic Outreach Taskforce HOT

Q 11, 23, 35, 47. Please check which of the following categories best describe [group name.] [choices given] If you checked "other" please describe the type of group. [not health/mental health, developmental disabilities, or education related group.]

1	It is a group to help ensure scouts with disabilities achieve desired rank, are fully included, and are accommodated as needed on campouts and during activities.
2	Services under the whole child model
3	Childcare
4	Administrative law judges, experienced legal professionals in Special Education
5	Parent group
6	Cómo deven las personas con diabetes alimentarse para sentirse bien
7	Policy
8	Respite/End of Life Facility for children w/life limiting conditions
9	Peer to Peer support group for all aspects of special needs parenting and family life
10	Special needs support group
11	Social Justice
12	Oversee juvenile hall in Napa, CA
13	Health/Mental Health/Developmental Disability/Education
14	Parent group at George Mark Children's House for children who are medically fragile and/or have a life threatening illness
15	Education, employment, health care, housing through lifespan
16	Social Welfare
17	Medical/ developmental/ educational
18	Learning disabilities but also supports all disabilities

Q 15, 27, 39, 51. Why did you stop participating on [group name]. [options given]. Please comment about why you stopped participating.

1	Contracted ended.
2	I am currently a member of the foundation, but the Teen Speaks up is just one time yearly event that Myself and my son who has Epilepsy attended.
3	I did not agree with he way they opperate.
4	To my knowledge, there has not been another meeting, but the organizers expressed plans to continue in the future.
5	it was difficult to continue participating due to the location and time
6	I was invited to speak at the March for Our Lives Rally and March as a parent of a child with special needs. This was a one time opportunity.

Please comment about policy / systems change. (Questions 17, 20, 29, 32, 41, 44, 53, 56)	
1	Well, there was a number of questions the group developed throughout the term of the committee, these questions were made for researchers to improve the way services are delivered to the community.
2	Tengo mi propio grupo de apoyo, soy líder del grupo. . . amo mucho ser un apoyo para cada familia y ayudar a encontrar servicios para sus hijos
3	Many families have been educated on their medical and educational rights, given access to resources, and we convinced the school districts to open new vocational programs and Circle of Friends peer mentorship programs.
4	I feel that the board is a way to inform the region about the system, especially how regional center work. The input we provide is used to educate via workshops and conferences.
5	I would say that participating in the FVofCA Advisory Council contributes to Leg Day, which has furthered policy or systems change or improvement
6	We are in the formative stages but are developing our scope and plans for advocacy.
7	Group ideas are implemented across the organization in areas including building design/wayfinding, patient education, nursing procedures, hospital operations, etc.
8	Self determination program will start in Q4 2018 state wide.
9	To understand the knowledge child care providers currently have for children with disabilities. To see if providers feel they need additional training on special needs and to feel confident to include them in a inclusive environment. In a survey that is being sent out.
10	Parent Participation on committees where policy decisions are being made have improved.
11	A lot of disability awareness has been raised that fosters inclusion in our community
12	Question not really relevant to my role on committee
13	In the OUSD there are now other Special Needs Advisory, Councils, we changed (our school) the Emergency District Plan,pertaining to evacuation plan
14	In a push to "go green" with payroll system the agency has transitioned to online procedure that has also resulted in a decrease of delayed payments.
15	I helped to start a Buddy Family program to pair new families with current families. I have made sure that special education teachers and speech therapists receive a classroom stipend. I have also advocated for field trips for the special day classes.
16	Alta Regional Center received approval for research into the early I intervention and special education for African American children.
17	We are much more visible and accessible to parents, students, professionals. I also represent us at the Joint Powers Board Meetings, I am confident the Superintendents are seeing our value in the districts, and starting to understand what FRCs do. I am looking forward to promoting Project Leadership to parents with our SELPA (districts).
18	Improve dyslexia screening and intervention, reduced suspensions, social skills supports to protect from bullying.
19	Code sepsis was created and implemented in ED first, through PAC/ED partnership, then system wide.
20	Collaboration with the school principal to provide accessible events for children with special needs, installation of playground shade canopy for students sensitive to heat and sunlight, and classroom staff considerations for students who need more behavioral support.
21	Yes, we successfully added CACs to a bill's language.
22	It was a collaborative with priorities identified by the group to be compiled by the organizers.
23	We hired an inclusion expert for the district, and created several parent training workshops.
24	The group is the planning committee of an annual parents conference
25	This group is to help individual families it does not have internal policies per say. I know I have helped on the individual level.

Please comment about policy / systems change. (Questions 17, 20, 29, 32, 41, 44, 53, 56)	
26	We partnered with Solano county and local groups of interest to creat a website of resources for speacial needs families. Solanocares org/disabilities
27	Administrators, staff and parents are in better communicayion
28	I created a needs assessment for the A School Age Medication Consultation Clinic at Children's Hospital Los Angeles. The objective was to measure the use of Family Centered Care within the staff and faculty. The survey was distributed, collected analyzed and the results presented to administrators. Next steps include policy and strategic planning with staff and families.
29	Advocacy on all levels has been achieved and continues to progress.
30	I believe the family input and questions have influenced the communication between CenCal and affected families as they absorb oversight of the CCS program.
31	As Parliamentarian and special needs advocate within the group, all events are now planned with special needs students in mind.
32	There were policies in place to keep parents and caregivers out of their children's classrooms and limit the exposure parents had to their children's classes - we worked to eliminate those restrictions.
33	We are currently redefining our purpose and direction. I can see very positive impact on the horizon.
34	Research into educational interventions for people with this developmental need. Increased family support. Sharing of strategies
35	In addition to this speaking opportunity with my son present, I've also attended district breakout sessions on school safety and have advocated for making plans that include children with special health needs.
36	Parents/professionals working together around policy changes to improve funding for programs such as this.
37	The school was not prepared to work with me and the information I shared about children and families with disabilities. Although FAPE is a mandatory component in the school system. The application of its policies are not always implemented accurately. More advocacy work is needed here.
38	Statewide review in progress
39	RSK Parent Leaders help support parents of individuals with new diagnoses - we also provide background and perspective to lawmakers and policy makers to implement change.
40	I give the link to "family voices in your state" which helps people find their local resources
41	We were forming but then the Coalition for SWD got going and consumed our attention.
42	more support for teachers
43	I do assessments for both early education centers and mentor site directors. I have been keeping them abreast of laws and rights for those with disabilities and specific, guaranteed rights to a free appropriate public education (known as "FAPE").
45	Policy change in MO search and rescue, state agency accountability. To be continued..
46	We decide how funds are spent (mostly). It's a decent platform to engage parents and inform of how systems and policy change will make a difference.
47	Getting resource guide back online (almost done)

Q 60. Please use this box to give more info about the group or groups that you are thinking about joining.

1	Específicamente Educacion especial en el Distrito Escolar y grupos de padres con niños con autismo
2	Todos los necesarios para ser un apoyo para todas las familias que lo necesitan.
3	COPAA. Coalition of Parents, Attorneys, and Advocates.
4	I have broke ground on forming a foundation that will provide iep and 504 avodcacy for low income familys,products for students with disabilities and struggling students that will aid them in better accessing fape and education parents and familys on student and parents rights. We will also go into schools and teach inclusion practices for students.
5	None
6	Need to investigate the time commitment more.
7	Support for Families Board
8	Advisory group for Respite House.
9	National Alliance for Mental Illness
10	Would like to approach colleges to find out what is offered to help really transition students and advocate for more for every learner
11	HealthRIGHT360, FOTEP, TI (Female Offender Treatment and Employment Program on Treasure Island) and they are workung on Family Maintanance plu Reunification.
12	I'm not entirely sure at this point but if an opportunity presents itself I would consider
13	Any groups pertaining to wheelchair accessibility (cut outs on sidewalks, cars parked across sidewalks.,etc)
14	Above selected are areas of interest
15	Wrap around seVICES
16	I have become legal guardian for my granddaughter last year and this is my son, the adult child with mental health issues, not an adult at the time but the kid I came to the training about. Anyhow I would like to learn more or learn again how to address policymakers about specific issues.
17	I have developed physical issues and I don't know how long it will be until I can participate in a group.
18	we no longer live in California
19	My daughter, Alexandra, (age 30yrs.) died 2/6/2018. Without the Project Leadership Training I received, I wouldn't have been able to work with her doctors & hospice. I saw her decline in health, and brought our daughter home. With the help of hospice she died in familiar surroundings, peacefully, with family who loved her. As I grieve the loss of my precious daughter, and make sense of a world without her, I'm certain there is a place for my skills to help other families. My 30-years of experience working with insurance companies, school districts, the regional center, medical professionals, teachers & government agencies such as Medicaid and IHSS, has prepared me to be an advocate for the developmentally disabled community. The majority of the population don't know the lovely people who are in this group. I want to be the voice for those who don't have one!
20	I am currently undecided at this time. Looking to see, where I would be a good fit and needed.
21	Social Justice
22	I have not actively participated in the CAC I am currently part of, but I plan to. It was mostly inconvenient times or current life stresses that kept delaying my attendance.
23	Santa Barbara Women's Political Committee, Indivisible Santa Barbara. I'm already an Awareness Coordinator for the Cornelia deLange Syndrome Foundation but want to get more active.
24	NA

Q 60. Please use this box to give more info about the group or groups that you are thinking about joining.

25	I would like to advocate for more inclusion spots in sfusd preschool. I don't know how to start this. I think preschool is best time for kids to be included with peers with td. I didn't even know it existed when we were in preschool. I'd also like to work on raising quality of extended school year. Maybe start with data. How many families refuse it and why? I think 50% if those who qualify do not attend. I suspect it's due to staffing changes and location changes. It could be other factors. A survey to find out why could be a good start.
26	I'd like to join a committee that affects policy statewide for children with special needs.
27	May consider joining a city or county council or advisory group for Scdd

Q. 65. Please describe the issues that you have communicated with any legislator or other elected official about during the last year.

1	Para pedir una carta
2	Numerous. Mostly about changes to healthcare.
3	A play ground for students with physical challenges
4	The need for medi-cal and denti-cal services for children and young adults with disabilities,the restoration of recreation and camp services, accountability in our schools for lack of following law,telling my sons story, a project I have started called science park and disability rights. The need for services for low income families.
5	It's been a busy year, I sent emails every time there was a threat to our families, like Affordable Care Act. Every time I receive info on threats from State Council, Family Voices, Arc
6	About not rolling special ed funds into the general fund.
7	issues connected to FVofCA leg day; transition of services within CA and the challenges therein
8	Maintaining birth control services through planned parenthood
9	Medical/ CCS
10	I spoke about the need to raise reimbursement rates so that people can obtain services, and/or not have to wait so long for them.
11	CCS services
12	Home nursing, Obamacare, Trump bullshit
13	getting FDA approval for an Epilepsy medication and Medi-cal benefits to not to be cut for my son with Epilepsy
14	Equitable pay rate for working disabled individuals.
15	Health care, child care, mental health
16	Education, Special Education Policies, Mental Health, Sickle Cell Disease budget and changes to Medi-cal
17	Health care concerns
18	How can we assure universal healthcare and also keep serving the special needs population
19	Budget cuts for special education
20	funding for medi cal, funding for people with ID
21	Special Education
22	Improving access to medical choice, expressing displeasure with the one size fits all medical paradigm
23	Special needs parenting and full time employment . Lack of flexibility in the workplace.
24	Regional and national legislation affecting cshn that is being jeopardized by this administration.
25	Concerns related to the Presidents budget cuts (Heath care) and related to potential legislation.
26	Just received info on current health Care or representative issues and reminders
27	I have sent emails when asked regarding bills to either vote on or note support. I apologize I can't be more specific, my main focus was on caring for my daughter.
28	Special Education law and resource provisions, including Developmental /Disability /Aging resource provisions.
29	Potential Congressional changes to the Medi-Cal/Medicaid system. Supporting ABA services through Medi-Cal Managed Care Health Plans
30	Recreational funding, immigration, medicaid, IHSS, environment, education, special education.
31	Access and infrastructure for pedestrians and disabled people
32	Informational on services.
33	Pushing for change in education without cutting funding to special education in the state of AZ
34	Regional center restoration and SSI
35	Reinstatement of funding for social and recreational services through regional centers.
36	Mainly I've tried to bring attention and importance to assembly bills that I am passionate about.
37	Cuts to mediCal, ccs, single payer health care, saving Obamacare
38	Children's mental health. Governor's budgeted allotment for home health.
39	affordable housing, restoring pay rate to caregivers
40	Cameras in special education classrooms.
41	Family empowerment center bill, special education funding and accountability and CACs

Interaction with media.

Q. 66. Have you interacted with the media during the last year? Please check all the answers that apply. (n=81)		
	No. responses	Percent
No.	67	83%
Yes, I've written letters to the editor or similar.	1	1%
Yes, I've participated in a press conference.	0	0%
Yes, I've provided one or more interviews to the media.	10	12%
Other (please specify)	8	10%
<input type="radio"/> Si estube en una entrevista con la universidad de san Francisco contando mis experiencias con un niño con un niño con discapacidades y las neseidades de salud		
<input type="radio"/> Paneles con médicos		
<input type="radio"/> i have been interviewed a few times for research on the treatment of students in special education.		
<input type="radio"/> I began producing and hosting my own radio show dedicated to issues of importance to people living with disabilities. I also play music.		
<input type="radio"/> Annual Review		
<input type="radio"/> I was quoted in our local media after March for Our Lives but wasn't interviewed.		
<input type="radio"/> Press releases and sac news and review recently reached out to me through SCDD		

Q. 67. Dates interacted and issues addressed with media (n=13)
<input type="radio"/> Agosto a Noviembre 2018; Salud y educacion
<input type="radio"/> Septiembre hablamos sobre temas relacionados cómo es vivir diario con un niño con necesidades especiales
<input type="radio"/> I've been interviewed a few times. Usually I see an e-mail from you guys saying the press wants to talk to someone. If I qualify, I contact them.
<input type="radio"/> Please see answer above. 96.5 FM KUBU Public Access Sacramento. Weekly shows started in February. The show is called Cultural Crossfade, which airs Sundays from 10-11am.
<input type="radio"/> Discussion after Health Summit in DC, published Photo Essay about my son.
<input type="radio"/> There have been two articles, one of them talks about our journey to mental health, and the most recent about accessing services through medical, they have been released in different media such as kiddata, family voices, and california health report, first one was issued in June and the last one this month
<input type="radio"/> Sacramento BEE
<input type="radio"/> 6/18 Awareness KEYT, KTYD, KJEE
<input type="radio"/> Santa Barbara Independent and Noozhawk or EdHat. February 14, 2018
<input type="radio"/> UCLA Urology Newsletter - Winter 2017-18, The Painted Turtle (interview for future fundraising efforts), Kaiser Health News (interview for article to be released on durable medical equipment), Support For Families' Newsletter - Fall 2017
<input type="radio"/> Special ed student outcomes in Sac City USD, CAC resignation, district failing students, failing to respond to and address issues in the audit by the Council of the Great City Schools.

“Other” advocacy activity participation.

Q. 68. During the last year, have you participated in any of the following advocacy / leadership activities? Please check all that apply. (n=78)		
Speaking or presenting individually or as part of a panel.	33	42%
Participating in rallies.	16	21%
Partnering with providers to advocate for children with special health care needs.	23	29%
Providing testimony / giving public comment.	21	27%
None of these advocacy activities	23	29%
Other (please specify)	8	10%
○ Médicos de la universidad de medicina en San Francisco, California		
○ presentacion de el programa help me grow a un conferencia de padres en el chabot collage		
○ Attending IEPs and Fair Hearings for special needs children as their pro bono advocate.		
○ met with over 20 legislators or their health aides in Washington DC advocating for continued medi-cal benefits for children like my son who have Epilepsy, on behalf of the Epilepsy Foundation		
○ I spoke to 250 Labor and Delivery nurses		
○ RFA (resource family approval)		
○ School board		

Q. 69. If you checked that you have provided testimony or offered public comment, please provide more details about where, when and topics. (n=26)

1	En support for families and children with disabilities en Noviembre 2018
2	En el programa legacy. . . di mi testimonio. . . sobre no firmar ningún papel si no estás seguro de entender lo que se dice. . . por que a mi hijo le quitaron su terapia y yo firmé sin entender . . . Y desde ese momento bajo mucho más en su educación
3	Temas, como es vivir con un niño con necesidades especiales
4	several times at the state Capitol, I frequently speak to health care and education policy. Most of my efforts are local with my school district, I attend every school board meeting and city council meeting. I speak frequently to special education, treatment of students with disabilities and the need to make west Sacramento a more inclusive community. I have had amazing feedback.
5	Kaiser Permanente Spasticity
6	In January, I spoke (outside) on the Capitol as part of a presentation panel to have MediCal funded by Congress. I was the parent representative among legislators, doctors and advocacy groups.
7	N/A
8	Trump BS, Nursing and Patient Relationships, Resident Training at UCSF
9	At one of the Project Leadership graduations, I was invited to be part of the panelist to talk about my experience after I graduated PL
10	March of 2018. The launch of solanocares.org/dissabilities website. June 2018 became a board member for solan local child care planning council Every wednesday morning from june 2015 to present at p.e.p support group meeting. March 2017 state council of developmental disabilities board meeting to save vallejo office Feb 2018 city council meeting to advocate for wage increase for ihss workers
11	For Childrens Hospital Foundation, For changes for children with special needs in the school district, legislators, Sickle Cell Disease Association Of America
12	Health care related. Speaking on issues related to underserved populations.
13	social media, cards and letters
14	Transition to adulthood services for children and youth with special healthcare needs
15	At the PAIMI meeting in Sacramento
16	Children in the foster care system
17	city council meetings
18	I provide my testimony in the annual disparity meeting in Harbor Regional Center on March.
19	N/A
20	CA State Capitol
21	March for Our Lives
22	Public comment on school board meeting.
23	SSI hearings and bills that impact families
24	I do a lot of this type of public speaking at the Joint Powers Board meetings, where irate parents can be found. I share about my experience working with school districts and our SELPA, Regional Center etc. How to address and engage the people working with their children in ways that can help achieve peace of mind, and the services they're wanting - by developing strong relationships with all who work with their children.
25	I was on 2 panels to speak with Ucsf doctors and sfsu ape teachers about parent perspectives
26	Sac City USD School Board, visits to legislators, and with analysts for senate and assembly ed committees

Q. 71. If you would like to comment about the support offered by Family Voices of California / Project Leadership, please do so here. We would like your suggestions about what types of opportunities/assistance would be most helpful to graduates in the future. For example, what types of speakers would you like to hear from at graduate events and webinars?

1	Abogacia por niños con discapacidades
2	A las familias graduadas como un ejemplo que si podemos participar en conferencias públicas y anivel mundial
3	I am currently in law school and would appreciate any help you could provide to connect me with organizations that might help me develop my skills to help children and families through externships with them.
4	I would like to hear from self advocates.
5	While I feel my training has helped me enemezily personally and in general to help families as individual. Due to me personal struggles with my severely disabled son I find that my finding time and energy to help on a higher level is difficult. Often I can't find child care to attend meetings even I really think I can make a change in group or organization. If I knew I could call a service that is paid for to watch my son so I can attend meeting I would.
6	I'd love the support you provide, because you motivate me to continue advocating and the education we receive at your events very important to stay current
7	I think you all are doing a great job! I think more info on communicating, dealing with rejection, how not to get discouraged, and workshops or separate interest areas that are more niche, like my radio show, or another parent that wants to give classes in a park. How to foster and promote our individual projects, to make more of an impact and keep motivated. Thanks!
8	More paying job and more college opportunities for adults with Disability
9	Be more active in fostering collaboration and ongoing communication.
10	Legislators who are working on the issues for children and young adults with disability.
11	None at this time.
12	I would love to hear about advocacy opportunities from organizations that are recruiting families with stories...in other words more opportunity to connect with advocates needed.
13	I think it would be helpful to send out emails to graduates of this program to keep us abreast of support opportunities available to graduates.
14	Great training
15	I have only attended one event over the past year. I loved the FV representative's presentation and interactions, but the political representatives/speakers lacked intellectual diversity. I felt that some of the political representatives just wanted to manipulate the parents to use as a prop for political objectives that weren't necessarily in the best interest of the medically fragile/complicated families. As a parent an 18 year old with severe autism, I have witnessed the increasing neglect of those affected by severe autism. Two of my friends with sons in a similar condition had to hospitalize their sons after severe behaviors because the Regional Center just doesn't have anything available to help. After one of my own son's "behaviors", I was sent to the emergency room and had something like 30 stitches in my face. Yet regional center could do nothing. My husband had to quit his job to care for our son. I had to hide in a locked room whenever my son wasn't at school so that he would not rip the stitches out of my face. We were informed that there is no emergency (or non-emergency for that matter) out of home respite for people like my son. We were told that our only alternatives were to admit him to the emergency room, have the police pick him up or keep him at home. Of course admitting him to an emergency room would have been cruel and harmful to him and probably to the hospital personnel as well who do not have the appropriate training in dealing with someone with severe autism. I imagine they would have just medicated him into unconsciousness. Yet two of my friends had to do just that - admit their sons to the hospital because they could not handle the physical outbursts. One was in for months before Regional Center was able to set up a round

Q. 71. If you would like to comment about the support offered by Family Voices of California / Project Leadership, please do so here. We would like your suggestions about what types of opportunities/assistance would be most helpful to graduates in the future. For example, what types of speakers would you like to hear from at graduate events and webinars?

	the clock in home support system. She was able to rent an apartment for herself, but that wouldn't be an option for most people. We are in crisis, but not one single political addressed it. California, in its effort to be everything to everyone, is failing in its most basic duties. I would like for someone to address that.
16	When you give us a project to work with, during the training. You should also give us the contacts, and try to connect us with the people who can help us to make reality our project. Many of us we really like to follow up our projects.
17	I would like to see more activities in southern CA by Family Voicesz
18	The reason I didn't participate as I stated before I was caring for my dying daughter.
19	I would love to meet and work with Alumni
20	Maybe something on how to choose best opportunities when you are primary caregiver and there are so many options. :) I want to be sure my time is used wisely and is making a difference.
21	I graduated from the program in 2014. I would appreciate a one day review class on Project Leadership and all of the updates. I would like for you to invite DDS Executive Director to give a presentation on the role of the Regional Centers across California and what to do if they are not following protocol.
22	great class.
23	Current policy.
24	Speakers knowledgable about mental health and how to navigate services for a loved one. While there has been more awareness, there continues to be ignorance and stigma amongst the general population and certain cultures.
25	Simply wonderful!!!

Q 73. [Q re employment since PL training – multiple choice.] Please use this space to say more about your job and how the Project Leadership training and networking has played a role (or has not played a role).

1	No nesariamente en un trabajo pero si en nuestras vidas cotidiana escuela y hospital
2	I've had a tax consulting business for nearly two decades. My advocacy skills are not useful here, but they are very useful in law school and in the free advocacy I do for members of my community.
3	I feel like I can be a great advocate and teacher if I had the support with my home situation. My son is severely impacted and finding support to care for my son is difficult so that can leave my home to attend meetings.
4	I am the Family Support Coordinator at Care Parent Network (Family Resorce Center), which educates and empowers family members to advocate for their children.
5	My work is not related to children with special needs.
6	I was an Interviewer for State Council on Developmental Disabilities working on the face-to-face state survey. It just ended recently. The training helped me feel confident in talking to other passionate but frustrated parents, and providing resources on how to get connected to a larger network of parents, like FVCA, for example.
7	I deal with all types of people Leadership has taught me to keep standing up for what I believe in and encourage others to do the same. In disability no don't mean stop it just mean find another way..
8	Right now my job is caring for a disabled husband and son
9	I am ihss worker for two of my children with dissabilities. I am confident in seeking the maximum amount of support possible for them.
10	I am working on a Fellowship at USC/Children's Hospital, I am also working part time as a Director for Early Childhood Education Site Supervisors. The Project Leadership Program has built my confidence, provided resources and access to help families with children with disabilities.
11	Im a Behavioral Technician for the West Contra Costa School District. I work with children with special needs. I also sit on the board to make sure all students and parents are getting what they feel their child needs etc.
12	I work with families in mainraining and reunifying them.
13	I am a paraprofessional in special education day class in Jefferson Elementary School District. My interest in advocating for my child led me to want to help other children in the school setting.
14	helped me with my confidence during advocacy
15	the training was incredible and did help me to become a better advocate for my son and in my work. I work as a Family Advocate and have been doing that since before I attended the training.
16	The biggest obstacle for me is the feeling that Sacramento is so in thrall to the medical industry and other big money contributors that our representatives will not have the courage to address the biggest problems. I believe Lucille Packard set up the foundation to give parents a voice, but I am unaware of the foundation doing anything to stop the wave of medical mandates and silencing of the voices of individuals in favor of big money politics. Did anyone say anything at all when the 21st century cures act was passed with a provision that it was now Ok to use experimental biologics and procedures so long as "risk deemed minimal". As far as I know, no identification of who gets to decide what risk is minimal. No mention that minimal risk for the population at large might mean maximum risk for subpopulations. So if you are asking for a skill I could use, I guess that would be the power to overcome the sense of futility in fighting forces that have overtaken our political system and have deemed my younger son and our family as acceptable collateral damage in their efforts to get out as many products to as many people as possible.

Q 73. [Q re employment since PL training – multiple choice.] Please use this space to say more about your job and how the Project Leadership training and networking has played a role (or has not played a role).

17	I am a parent support liason/ promotora for a pilot program aimed at increasing San Diego regional center service use for Latino clients underutilizing services. I teach families how to advocate for their special needs children.
18	My current job is part time email marketing for a Mom & baby fitness group. The position I had was prior to project leadership, so it didn't influence my work.
19	The skills are absolutely helpful in my role as PTA president at my boys' school.
20	It's changed my life in a million ways, mainly by introducing me to a network of amazing families and resources that impact all that I do for myself, my children and the millions of people I'm not related to but need lots of help.
21	Through informal networking the Director of a family resource center became interested in hiring me to join the staff.
22	During the last annual reunion, conversing with another leadership graduate lead me to become a family navigator with FRN in San Leandro.
23	My job does not directly relate to this training as I am working outside the field but the skills gained have been instrumental in my career.

Q. 79. We are interested in the education systems that you interact with on behalf of your child with special health care needs / disabilities. If you are comfortable sharing this information, please name the school district and city where your child attends school (example, San Francisco Unified School District, San Francisco):

1	Distrito escolar de san Francisco
2	Napa
3	Distrito escolar unificado de San Francisco
4	Murrieta Valley Unified, Murrieta
5	West Sacramento,ca Washington unified school district
6	Oakland Unified
7	My child is deceased, but I work w/families in Contra Costa School District
8	San Diego Unified School District, San Diego
9	SFUSD, San Francisco
10	Arcadia Unified School District, CA
11	San Diego Unified School District
12	Livermore unified
13	San Juan Unified. But our charter school at some point soon will be on its own
14	Twin river Unified School District in Sacramento, CA
15	WCCUSD, Richmond
16	SFUSD
17	Pomona Unified School District and Port View Preparatory Private non-public school that he attends
18	ESFRN
19	Oakland Unified School District, Oakland
20	None, but I am working in Elk Grove Unified School District.
21	Fairfield-Suisun unified school district - private school.
22	Los Angeles Unified School District
23	West Contra Costa
24	Mt. Diablo School District, Contra Costa County
25	Santa Barbara unified school District
26	Santa Barbara Unified
27	Seneca center. Mental health
28	Jefferson Elementary School District, Daly City
29	MVSD, Mill Valley
30	San Mateo Foster City Elementary School District
31	NVUSD
32	Sweetwater School District
33	currently my granddaughter is a client of RCEB.
34	Bellflower Unified School District
35	Sweetwater union high school district , Chula Vista CA
36	Arcadia school district
37	Castro Valley Unified
38	Oakland unified School district
39	no longer live in CA
40	Elk Grove Unified School District
41	Hesperia Unified School District, San Bernardino County
42	Riverside Unified School District, Alcott Elementary School
43	Santa Barbara Unified School District, Santa Barbara

Q. 79. We are interested in the education systems that you interact with on behalf of your child with special health care needs / disabilities. If you are comfortable sharing this information, please name the school district and city where your child attends school (example, San Francisco Unified School District, San Francisco):

45	Berkeley Unified School District
46	SACRAMENTO UNIFIED SCHOOL DISTRICT
47	Graduated already.
48	Gilbert Unified School District, Gilbert, AZ
49	Oakland unified
50	Corona Norco
51	both Whittier Union High SD and East Whittier City SD
52	Sfusd
53	Torrance Unified, Torrance
54	West Contra Costa Unified School District, Richmond, CA
55	San Leandro Unified School District, San Leandro
56	Elk Grove unified school district
57	Sacramento City USD, but pulled child to private school

Q 80. As part of our ongoing networking / mentoring services, it would be helpful to know more about the agencies / services that your family uses. The following questions are, of course, optional, but we would appreciate your feedback. Please check all of the following insurance and agency programs that your family uses: ["Other" listed below].

1	Shriner's Hospital for Children
2	The checked agencies are all the the agencies my daughter used during her lifetime.
3	We USED to use Regional Center for in-home ABA from 2009-2016 before we switched insurances, but since then, we have not used any services. We have private insurance, but have not done any further services.
4	Thank you
5	AHCCCS/ALTCS
6	Medi-Care ESRD
7	Alameda County Behavioral Services

Q. 81. In order to serve you better and improve our services, we would appreciate information about your child's health and disability challenges. This question is, of course, optional, but we will appreciate your feedback. Please check all that apply to your child (or children). [Below is "please provide further information here.]

1	i don't have children
2	Defective X chromosome
3	partial trisomy
4	Transplant
5	Global dyspraxia
6	Restrictive Airway Disease, Compressed Lung
7	Elhers Danlos syndrom type 3
8	Sickle Cell SS Disease
9	Severe cerebral palsy
10	Cerebral Palsy with global developmental delay, intellectual disability as well as Autism spectrum disorder
11	Very high functioning so his future College ideas are what is a challenge right now
12	Angelman Syndrome
13	My granddaughter doesn't have a specific diagnosis but she's receiving P/T and Specialized Instruction.
14	Chromosome 18 p minus
15	My son had cancer.
16	Severe Asthma
17	My daughter had Aicardi Syndrome. This syndrome usually affects only girls. the average lifespan is 18/years. Aicardi Syndrome left her severely developmentally disabled. Alexandra couldn't walk, talk, or see. She was dependent for all her personal needs. She couldn't hold anything in her hand, so she had to be fed all her meals. She wore a diaper. She never developed beyond 3/months old in abilities. At six weeks she began to have infantile spasms and the spasms continued to become seizures. She had seizures her entire life. She was on 4-5 anti convulsant meds, & this prevented the seizures from breaking through, but on EEG's seizure activity was still evident. She developed her own way of communicating which I called "angel speak". Depending on the pitch, the volume, and frequency I could usually determine if she needed a diaper change, was hungry, a grand mal seizure was coming, she didn't feel good, or she just wanted to 'chat'.
18	Global Processing Disorders
19	My son has Cornelia deLange Syndrome. He has visual and hearing impairment. He has apraxia and uses gestures, signs, a communication device, and a handful of spoken words to communicate. He has spastic diplegia, wears AFO's, and didn't start walking independently until he was 10 years old. He has GERD, a heart defect, and asthma. He has an intellectual disability and spends part of his day in a life skills class. He has started behavior therapy for self injury and aggression. He loves riding horses which has greatly improved his balance and strength.
20	.
21	Primary diagnoses are ASD and CP
22	Heart condition
23	Diabetes and Celiac,in addition to all I checked off.
24	Williams syndrome
25	2x renal transplant
26	diagnosis: Bilateral Perisylvian Syndrome
27	Learning disability