

FVCA Annual Report June 2012-May 2103

FVCA is a statewide collaborative of 8 locally-based parent run Council Member Agencies (CMAs) working to ensure quality health care for children and youth with special health care needs. FVCA works to be ***“The voice of families, the vision of quality health care, the future for children and youth with special health care needs”***. FVCA provides information and a forum for parent centers and families to advocate for improved public and private policies, builds partnerships between professionals and families, and serves as a vital resource on health care.

From June 2012 to May 2013, CMAs provided **7,166 families, (19,469 duplicated)** with culturally and linguistically competent, individualized information and support in local communities. Languages include English, Spanish, Cantonese and Mandarin. Council Member Agencies provided **2,884 (unduplicated) families** with workshops, trainings and presentations, including trainings on choices regarding health care, partnering with professionals, health delivery models, leadership, and health care. During this 12 month period, CMAs also provided **1,412 providers (4,305 duplicated)** with individualized information and support in local communities. Council Member Agencies presented **1,930 (unduplicated) providers** with trainings and presentations such as: choices regarding partnering with parents, health delivery models, family centered care, and health care.

This year’s 2013 Health Summit and Legislative Day in Sacramento proved to be a great success with a total of **103 participants, including 38 parents or adult family members, and 6 youth**. The attendees represented diverse areas of the state from Humboldt County in the north to San Diego in the south. Evaluations of the Summit showed 97% strongly agreed that the Summit increased their knowledge of services and resources for CYSHCN; 98% strongly agreed that they learned new information about policy issues that affect CYSHCN and 91% strongly agreed that the support, information and resources they received at the Summit helped them feel more confident about getting their children the health care and services they need. One parent participant said *“I want to be a Mom – not an insurance cost analyst. However if we are going to be making those decisions then we should be at the table of the (policymakers) who are making decisions.”*

FVCA continues to hold free monthly Webinars related to many varied topics regarding health care for CYSHCN. For the 2012/2013 reporting year, **more than 425 individuals attended our 9 webinars**. The attendees are a very diverse group ranging from health care providers, advocates, parents, and youth with SHCN. Evaluations from each webinar continue to prove that these presentations are valued highly and provide much needed information. Presentations were: "Update on the State Budget and May Revise: Where Are We on Issues Affecting Children?"; "Help Me Grow"; "Educationally Related Physical and Occupational Therapy"; "What You Need to Know about Changes to MediCal and Healthy Families for Children with Special Health Care Needs"; "Getting the Most Out of Your Health Insurance"; "The Affordable Care Act and Exchange – What are the Specifics?"; "Regional Centers and Insurance Companies – Who is the Payer of First Resort?"; "In Home Support Services"; and "Educationally Related Mental Health Services"

FVCA provided additional information through the FVCA F2FHIC listserv, website and newsletters (including, but not limited to, resources from Family Voices National, legislative updates, and training or funding opportunities). The listserv provides a venue for families, professionals and CMAs to raise questions, share ideas, and locate resources. There were **59,091 listserv members, 70,899 newsletter subscribers and 3,242,268 website hits.**

Several of FVCA's CMAs are involved in the Help Me Grow (HMG) initiative in CA. They are involved in all aspects including being a telephone access point, providing community outreach, health care provider outreach as well as data collection and analysis. Two FVCA CMAs are used by the CA HMG Initiative as the models for other counties interested in learning how to implement HMG in their local areas.

Some CMAs continue to renew their Parent Health Liaison contracts with their local Title V program (California Children's Services - CCS) and continue to train CCS staff on family perspectives, help Medical Therapy Units (MTU), eligible families access services, and provide conflict resolution assistance for CCS staff and family members.

FVCA maintains an active Facebook page. Several posts are made per week, updating FVCA Facebook friends on current "hot topics" about CYSHCN: upcoming meetings, webinars and sharing relevant posts from FVCA CMAs and other health care organizations' Facebook pages.

FVCA presents at the annual Family Resource Supports Institute. It is "the" annual conference for providers who work with families of children birth to three in CA (this includes Family Resource Center staff). This year on March 15, 2013, FVCA presented *ACA and Early Start Family Resource Centers*. The first part of the presentation focused on an overview of the ACA and was followed by an interactive session to assist attendees to think about all the ways they might be able to participate. It included an extensive list of ACA resources. There were 51 attendees.

One FVCA Council Member agency participates in the Special Needs Committee of the Alameda County Medi-Cal home project that joins advocates, providers, community partners and parents in discussions of issues facing CYSHCN in Alameda County. Alameda has a family leadership in this project, supporting 12 family leaders who serve on a variety of governance committees. Their services are Alameda County First Five. The project's success was recently evaluated via survey and published by First Five. This CMA has worked on issues such as families who are transferring from Healthy Families to Medi-Cal and its impact on services, as well as the impact on families of the need to access insurance funded services before being able to access California Early Start.

Using the combined resources of FVCA and volunteer efforts, Alpha Resource Center (Santa Barbara County CMA) had several community parents they serve present their stories to the local Board of Supervisors before a packed audience. They told how Title V (CCS MTU) services have helped their child achieve so many goals that helps pave the way to successful inclusion in their schools and communities. One of the Supervisors arranged for the families to meet with the Santa Barbara County Director of Public Health and a full meeting was scheduled and held with program directors and another District Supervisor. Family concerns were heard and lessons were learned about local politics and county departments. In light of continued correspondence with the Public Health Dept. and two members of the Board of Supervisors, Alpha RC was assured that the plight of these families will continue to receive recognition. **Three stakeholder meetings where parents can voice concerns and work with CCS officials to better understand and resolve issues have been scheduled in 3 locations around their county.** Parents are actively urging other families to attend these meetings. A report back to the Board of Supervisors is planned by the families and Alpha. Alpha working as a FVCA Council Member will be facilitating presentations and continuing to work with families in enhancing advocacy efforts on behalf of their children with special health needs.

FVCA worked with local CMAs to hold 5 focus groups (in English and Spanish) for a researcher at the University of California San Francisco Medical Center. The topic of the focus groups were “Improving the Care Experiences of Families with Children with Special Health Care Needs: Developing Recommendations for Strengthening Services, Supports and Resources”.

FVCA CMAs participated in CA health related organization convenings/conferences. At one of these meetings, “Health Insurance and Regional Centers : Family Centered Care – Building a system that works for Families” a CMA gave the keynote address and FVCA CMA participated during the 2 day meeting in breakout discussions to strategize on policy system development and improvement.

FVCA CMAs met with Lucile Packard Foundation for Children’s Health to identify priority issues for families of children with special health care needs in accessing health care in CA. These meetings culminated in a Legislative Briefing at the State Capitol addressing CSHCN in California. The title of the presentation was “The Experience of Families Accessing Health Care in California”. This briefing was attended by many legislators, their aides, providers, health organizations and families.

FVCA provides individualized support to families and providers to find local resources and services for their youth who are transitioning. CMAs host transition workshops and roundtables for families in English and Spanish. FVCA CMAs also helped providers better understand the family perspective by hosting groups of graduate students who listened to panel discussion on issues of concern to transitioning students and their families. FVCA CMAs have developed comprehensive Transition packets and use those packets in trainings. CMAs hold transition conferences for CYSHCN such as "Going to College with Disability".

FVCA continues to develop relationships and collaborate closely with other key organizations dedicated to CYSHCN. Some of these organizations are:

- ◇ **Lucile Packard Foundation for Children's Health**
- ◇ **University of California San Francisco**
- ◇ **Disability Rights California**
- ◇ **HealthNet of California**
- ◇ **The National Alliance to Advance Adolescent Health**
- ◇ **California Network of Family Strengthening Networks (CNFSN)**
- ◇ **Patient and Family Centered Care Partners**
- ◇ **Children's Regional Integrated Service Systems**

FVCA holds monthly Council meetings, for which the Steering Committee approves/revises the agenda in advance. During these meetings, members collectively review current and potential projects and provide oversight to staff to ensure execution. Minutes of each meeting are recorded and distributed to all council members, with tasks and deadlines printed clearly therein. We set dates for planned project activities in advance and it is the job of the FVCA Manager to ensure projects are executed in a timely manner. The FVCA Manager also ensures that FVCA Council members submit their data on time, reviews the data for inconsistencies, and provides TA to council members to ensure timely and accurate collection of data. Each FVCA council meeting begins with members recounting (recorded by FVCA Manager) tasks completed each month. In addition, FVCA Manager meets with lead council agency Support for Families for regular supervision meetings to prioritize, problem-solve and work on projects together.

California activities regarding ACA are a key focus for FVCA since it will greatly impact how CSHCN are served. Our focus will include webinars, information listserv, and discussions. Tracking of those activities will include quantitative measures such as documenting the numbers of webinars, the attendees and qualitative measures such as collecting impact data regarding attendees' perspective on how useful the webinar was in their understanding of the ACA.

FVCA utilizes quantitative and qualitative tools to measure project effectiveness and assess impact of project components. Each of the 8 council member agencies tracks quantitative information about families and professionals they serve, as part of a collaborative member of FVCA. They also collect qualitative information by reporting on questions to families and professionals. Each Council member agency commits to making 4-5 calls per month to ensure FVCA meets its annual target of 93 calls. In addition, FVCA evaluates all trainings and webinars it provides as well as activities (such as the Summit) and conducts analysis when possible. FVCA staff are in the habit of recording all FVCA activities and staff activities to ensure that we record our successes, efforts and initiatives for

reporting and other purposes.

FVCA continues to match families with media sources so personal stories, experiences and awareness of issues for CYSHCN are shared with the general public. For example, in August 2012, FVCA matched 2 parents with the *Bay Area Parent Magazine* where they told their story about parenting newborns with disabilities. In December 2012, *SF Chronicle* covered a story of one parent's concerns with the upcoming Healthy Families transition to MediCal.