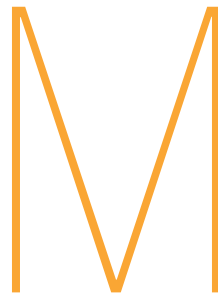


## OVERVIEW OF SERVICES FOR FAMILY SUPPORT

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Misconceptions and stereotypes about disability continue to negatively impact people with disabilities. Children, youth, and adults with developmental challenges and special health care needs are often misunderstood by the public due to their special need, especially if they have an “invisible disability” (e.g., mental illness). Children may be chided and bullied by peers, and it continues to be an accepted social practice to exclude children, youth, and adults with disabilities from everyday activities. Segregating those with disabilities in specialized programs, or excluding children and youth from educational and recreational activities premised on the idea that the staff does not have expertise in dealing with them, interferes with the full integration of these children and youth in community-based services.

Owing to these misconceptions, children and youth with special health care needs frequently face social isolation, poor self-esteem, and failure in school. When compared with their peers without special needs, CYSHCN do not fare well across many indicators. For example, they are more likely to have had an emergency room visit. According to the 2003 National Survey of Children’s Health, 31.8% of children with special health care needs had at least one emergency room visit within the last year, compared to only 13.9% of children without special needs (CAHMI, NSCH, 2003). They are at significantly higher risk for involvement with the juvenile justice system. Children with special needs are more likely to struggle in school; among children ages 6-17 in California, 20.9% of those with a special health care need had repeated a grade compared to 7.8% of those who did not have a special health care need (CAHMI, NSCH, 2007). Further, children with chronic medical conditions are more likely to need mental health services; are more likely to be victims of abuse and neglect; and are more likely to be unemployed or have lower earnings if they are employed as adults (van Campen & Cardol, 2009).

The system of services for children, youth, and their families poses many obstacles to families; without adequate coordination to provide seamless care, families are confused by a variety of regulations, eligibility requirements, and other details. Difficulties in obtaining vital information and accessing needed services are compounded for families who live in poverty; speak a language other than English; have cultural norms that are in contradiction with assertive advocacy; or have had previous negative experiences with government services.

Whether families find out in the hospital, at a doctor's office, at a regional center or another community-based agency that their child has special health care needs, they face a confusing maze of services and systems. As children grow older and become more independent, they need to understand the systems that serve them. Although many systems have case managers, families and youth often take the primary responsibility for coordinating their care across systems, and need ongoing information, education, and support. They need to learn the intricacies of the different systems and how to become partners in making decisions about their own care

A variety of cost-effective community-based resources works together to assist families in navigating these complex systems and regulations in order to obtain adequate and appropriate care for children and youth with special health care needs. Many of these community-based resources are rooted in parent-to-parent and empowerment-focused philosophies. Families of CYSHCN require many different kinds of supports to cope and survive. The following community-based resources help families to navigate the complicated service system; provide families with leadership training to most effectively advocate on behalf of their children; provide families with personal and peer support; provide care coordination; assist with service transitions; collaborate with service systems to more effectively serve families; provide families with resources and information; help families solve problems or issues arising with service systems; and fill gaps arising from the existing service system for children and youth with special health care needs.

**Jimmy has three pediatric specialists, an IEP, and receives services from the regional center; his mom is overwhelmed with paperwork. Staff from the local family resource center helps her to organize her extensive paperwork. She now has a binder with tabbed sections for medical, IEP, and regional center papers. The binder includes a medical history, plastic pockets for business cards, and blank sheets to record notes from phone calls and appointments. His mom feels more confident about her ability to help manage her son's care and feels a greater sense of control in a situation that is mostly beyond her control.**

### **FAMILY RESOURCE CENTERS (FRC)**

FRCs were formally established in 1997 when the California legislature authorized a statewide system of 52 parent-run family resource centers in recognition that family-oriented and parent-to-parent support services are key components of an early intervention (i.e., birth to age three) system for children with disabilities. California's 52 Early Start Family Resource Centers and networks are staffed by parents who have children with special needs. They provide information and parent-to-parent support to families of children from birth to 36 months. Each FRC is unique; some operate as independent sites and others are based in regional centers for persons with developmental disabilities, local education agencies, public health facilities, hospitals, or homes. As part of their contracts with the California Department of Developmental Services, FRCs are required to actively collaborate with other agencies serving families of children with disabilities and help families access early intervention services. FRC services may include:

- Parent-to-parent and family support
- Peer counseling and home visits
- Information and referral
- Public awareness
- Parent education

- Support services in many languages
- Transition assistance
- Support services in urban and rural communities
- Newsletters
- Resource libraries
- Websites
- Parent and/or sibling support groups
- Telephone advice and support lines

### **FAMILY EMPOWERMENT CENTERS (FEC) AND THE CALIFORNIA ASSOCIATION OF FAMILY EMPOWERMENT CENTERS (CAFEC)**

CAFEC is comprised of 14 FECs across the state. CAFEC provides information, resources, technical assistance, and systems change advocacy for a state-wide network of local family empowerment centers. FECs provide family education, empowerment, and parent-professional collaborative activities for families of children with disabilities ages 3-22 years old. California FECs receive funding through the California Department of Education, and must meet specific criteria, centered mainly on the provision of education. Several California FECs also receive funding from the California Department of Developmental Services in addition to the money received by the Department of Education, and as such, these organizations are classified as both FECs and FRCs. Some include:

- Training and information that meet the needs of the parents and guardians of children and young adults with disabilities
- Peer counseling and home visits
- Working with community-based organizations
- Training and support to parents and guardians of children and young adults with disabilities
- Participation in decision-making processes and the development of individualized education programs
- Promoting positive parent and professional collaboration with local education agencies, special education local plan areas, and other community agencies
- Participation and support of surrogate parent training

### **FAMILY VOICES OF CALIFORNIA (FVCA)**

FVCA, a family-to-family health information center (a support center staffed by knowledgeable parents with primary funding from MCHB) was established through the linkage of two different groups, Family Voices National and Family Resource Center Network of California. Family Voices National is part of a national grassroots network of families and friends speaking on behalf of children with special health care needs. It was established in 1992 to ensure

that the health of children with special health care needs was addressed during the national health care reform initiative. Family Voices exists in all 50 states and consists of more than 40,000 families and friends.

FVCA is a collaborative of nine family resource centers across the state of California, representing urban, suburban, and rural areas. Family Voices of California receives private and public funding, and is funded in part through the Maternal and Child Health Bureau. FVCA holds a vision for the provision of parent health liaison (PHL) services across California, including information, education, and support to families and partnerships with medical institutions, CCS and other groups to address family-centered care, access to community-based services, and linkages from hospital to home. It has set standards of services for PHLs through a Parent Health Liaison Training Manual, ongoing trainings, meetings, and conferences specifically to build the capacity of PHLs, and provides ongoing support and technical assistance to existing PHLs.

There are currently three models of the PHL delivery system in California: county CCS programs, hospitals, and/or other health entities that contract with local Family Resource Centers to provide PHL services; county CCS programs, hospitals and/or other health entities that hire PHLs within their system; and Family Resource Centers that provide PHL services through other funding.

When provided by a family resource center, the scope of PHL services goes beyond any one institution helping families and youth integrate services across a variety of systems. The following benefits come from this cross-systems approach:

- PHL services include partnering with families, youth, and the professionals who serve them.
- PHL services provide linkages to community-based resources.
- PHL services provide ongoing information, education, and support.
- PHL services can assist in problem-solving with families and the professionals who serve them.
- PHL services include leadership building for families and youth so they can take an active role in their services.
- Families are more satisfied with the care they receive.
- The state demonstrates its valuing of family-centered care by providing resources to support families.

FVCA was also responsible for creating the widely used “Hospital Discharge Questions for Families of Children with Special Health Care Needs” (in English, Spanish, and Chinese). This tool includes questions designed by families of children with special needs, and families are encouraged to utilize the questions as a guide to ensure that they understand vital information before they leave the hospital (e.g., medical care, medications, equipment and supplies, insurance, respite, and transportation). By providing leadership opportunities for families

and youth, such as the Annual Health Summit in Sacramento, FVCA helps to keep families informed on local, statewide, and national policies affecting children and youth with special health care needs.

Family Voices seeks to improve the lives of CYSHCN through the following means:

- Improving policies and systems of care for children with special health care needs
- Providing information and education to families and professionals regarding health care for children with special health care needs
- Promoting family-centered, culturally competent, community-based coordination, and quality care for children with special health care needs
- Developing family and professional partnerships

### **PARENT TRAINING AND INFORMATION CENTERS (PTI) AND COMMUNITY PARENT RESOURCE CENTERS (CPRC)**

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PTIs and CPRCs serve families of children and young adults from birth to age 26 with all disabilities. They are funded by the U.S. Department of Education under the Individuals with Disabilities Education Act (IDEA). Each state has at least one parent center; California has nine PTIs and three CPRCs. The scope of work of PTIs and CPRCs includes:

- Training and informing parents and professionals about issues concerning children and youth with disabilities and the services available to assist them.
- Helping families obtain appropriate education and services for their children with disabilities.
- Working to improve education results for all children.
- Resolving problems between families and schools or other agencies.
- Connecting children with disabilities to community resources that address their needs.

### **UNITED ADVOCATES FOR CHILDREN AND FAMILIES (UACF) STATEWIDE FAMILY NETWORKS (SFN)**

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The UACF mission is to promote the emotional, behavioral, and social well being of children, youth, and families through transformational leadership. UACF currently operates three programs to meet its mission, a direct service program in two California counties, a statewide advocacy and training program, and a national training and technical assistance center. With the passing of the Mental Health Services Act, UACF's primary goal in California is to assist independent family organizations at the county level to identify their missions, incorporate, and build intentional and effective strategies to transform California mental health service delivery system for children.