



Families Helping Families of Children and Youth with Special Health Care Needs & Professionals who Serve Them

Summary of Information Reported to Family Voices by Family-to-Family Health Information Centers and the Family Voices Network, July 2005 through June 2006

Because the health care needs of children and youth with special health care needs (CYSHCN) are chronic and complex, many parents and caregivers struggle to find the resources and services that their children need. Other families who have experience in navigating systems of health care are frequently the best sources of assistance for families seeking information and support. Family-to-Family Health Information Centers (F2F HICs) and Family Voices (FV) Network Members provide this kind of assistance.

F2F HICs are federally-funded, family-run initiatives that assist families of CYSHCN and the professionals who serve them. Initially, organizations in 7 states were funded as F2F HICs by the Maternal and Child Health Bureau (MCHB). Subsequently, the Centers for Medicare and Medicaid Services (CMS) provided funding to 29 F2F HICs. The Family Opportunity Act, passed in 2006, will fund F2F HICs organizations in all 50 states by 2009.

F2F HICs vary in their organizational and funding structures. Some F2F HICs are located within family agencies that operate with support from multiple funding sources, blending funding from federal and state grants, foundations and private fundraising in order to carry out their work. Other F2F

HICs operate primarily with the funds that they receive through their federal F2F HIC grant. F2F HICs and FV Network-Member organizations are staffed by families whose experience in caring for their own CYSHCN has enabled them to fully understand, support and help other families.

Family Voices, Inc. provides technical assistance to F2F HICs and volunteer FV Network Members to support them in their work with families and professionals, including opportunities to work collaboratively across the country. Through the National Center for Family Professional Partnerships, Family Voices offers tools and guidance to build the capacity of these organizations to collect data reflecting areas of assistance that they provide to families and professionals. Family Voices collects and aggregates the information submitted.

This report summarizes data submitted by 33 funded F2F HICs and 12 FV Network-Member organizations from July 2005 through June 2006. The data includes information about requests for assistance, individuals served, type of information provided, problems with health care financing and involvement in broader-scope activities such as meetings, listservs, newsletters, handouts and websites.

"Families have received referrals for complex oral health needs and prenatal care for young adults with behavioral issues, among many other topics. Policy makers have received information about family care-giving issues and the need for our state to apply for a Medicaid waiver for children with developmental disabilities."

An F2F HIC



"(Our state) has faced several challenges related to funding of services for CSHCN this year. One in particular was the significant lack of funding for our Title V CSHCN program. Family Voices worked especially hard educating our partners on this issue...The result of the advocacy was that the Title V program received the largest increase ever."

An FV Network Member



Requests Received for Assistance



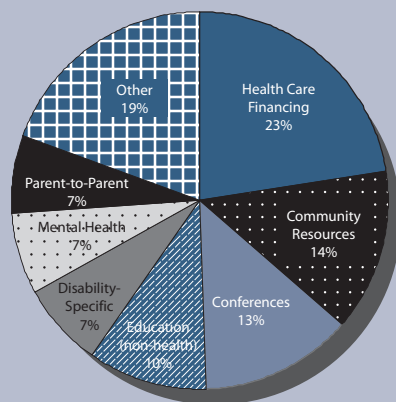
Avg # of contacts per family: **2.01**

Avg # of contacts per professional: **1.86**

Avg % of families from underserved communities: **43%**



Topics of Information Provided



"It is unbelievable the need for information. I am receiving calls from all over the state from individual families and hospitals."

An F2F HIC

Families and Professionals Requesting Assistance

Many families turn to F2F HICs and FV Network Members for assistance in finding and providing appropriate care for their children and youth with special health care needs. Professionals also seek assistance from family organizations in order to work more effectively with families, children and youth. From July 05 through June 06 the submitting family organizations reported:

- 61% requests for assistance from families (115,624)
- 39% requests for assistance from professionals (73,600)

Examples of the kinds of requests received from families included finding payment for medical care, seeking to talk with another parent, or looking for help navigating public health care financing programs. Examples of requests received from professionals included seeking a family perspective on materials, identifying parents to serve on advisory committees, or looking for information to help a family find community resources.

Because of the complexity of medical needs and health care systems, families and professionals usually make contact with an F2F HIC or FV Network Member more than once in order to obtain the assistance they need. On average, families made 2.01 contacts to get the assistance they needed, and professionals made 1.86 contacts.

F2F HICs and FV Network Members estimated that, on average, 43% of the families they served were from traditionally underserved communities, including families from diverse ethnic and socio-economic backgrounds and geographic settings. Those submitting data reported a variety of methods to identify this demographic information including participant self-identification, asking specific demographic questions, census statistics, primary language spoken and information about geographic areas served.

Information and Assistance Provided

In response to requests for assistance, staff at F2F HICs and FV Network Members provide many kinds of information to families and professionals, including helping parents understand a child's disability, find and pay for services, and find emotional and other kinds of needed family support.

Information about health care financing was the most frequently reported type of assistance provided. Additional topics of information and assistance that were frequently provided include: community resources, conferences and workshops, education, disability-specific resources, mental health, and parent-to-parent support. Other information topics reported include respite, oral health, transition, partnerships, advocacy, medical home and screening.

The President's New Freedom Initiative Report, "Delivering on the Promise" (March 2002), sets forth a goal of eliminating barriers that prevent people with disabilities from fully participating in their community. One way that F2F HICs work toward this goal is by providing information to families and professionals related to six performance measures (PM) of appropriate systems of health care for CYSHCN. Such information is provided through one-to-one contacts, meetings, workshops, conferences, and other partnership activities. In data collected from July 2005 through June 2006, F2F HICs and FV Network Members indicated that they provided assistance about:

New Freedom Initiatives:

- **Health Care Financing** (Medicaid, EPSDT, SCHIP, SSI, other public financing programs, related services in IEP/504/IFSP, and private insurance) in 53,443 encounters and 1,393 meetings (PM 4)
- **Community Services and Parent-to-Parent Support** in 49,085 encounters and 1,630 meetings (PM1)
- **Partnering with Professionals** in 11,753 encounters and 2,003 meetings (PM 2)
- **Medical Home** (access to care, care coordination, partnering with doctors) in 9,815 encounters and 1,248 meetings (PM 3)
- **El Screening** in 6,985 encounters (PM 5)
- **Transition to Adult Services** in 3,946 encounters and 1,220 meetings (PM 6)

Because of their expertise, F2F HICs and FV Network Members are often asked to review materials to provide a family perspective. These requests may solicit opinion and comments on surveys, agency reports, family-targeted materials and other kinds of publications. From July 2005 through June 2006, F2F HICs and FV Network Members received 4,230 such requests (2,664 from professional organizations and 1,566 from other family organizations.)

Assistance with Health Care Financing

Adequate health care financing is a critical component of quality care for a child or youth with special needs.

Families seeking help from F2F HICs reported nearly 20,449 problems related to health care financing.

- 70% of the problems reported (14,336) were about public financing programs, such as Medicaid, SCHIP, Title V, and SSI.
- 21% of the problems reported (4,264) were about health-related services in schools or early intervention programs.
- 9% of the problems reported (1,849) were related to private insurance.

Examples of health care financing problems reported include limits in amount or duration of needed services, denials of referrals to specialists, denials of eligibility for programs, lack of providers, and waiting lists for programs and services.

Within public programs, more health care financing problems were reported for Medicaid than any other program, reflecting the importance of Medicaid to many families of CYSHCN. Other problems reported related to Title V (19%), SSI (10%), SCHIP (8%), Developmental Disabilities Programs (7%), and other public programs (6%).

"We continue to keep an open line of communication with the Medicaid staff through monthly meetings with families and through my personal e-mails and calls with Medicaid. The continued presence of our families at events and legislative sessions keeps our issues in the spotlight."

An FV Network Member

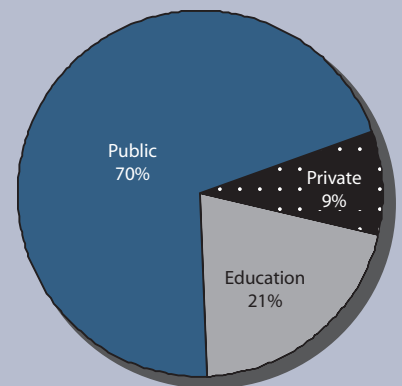


of Requests to Review
Materials from Professionals:
2,664

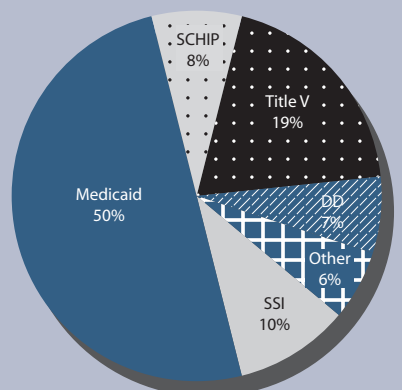
of Requests to Review
Materials from Family
Organizations:
1,566



Problems with Health Care Financing by Type of Program



Problems with Health Care Financing by Public Program



"Overall, the state of children's access to health and related services remains abysmal. Many families are overwhelmed and enduring extreme stress and fatigue from taking care of their children who need long term care and wraparound supports. . . Our family resource specialists have become very creative in finding resources and have earned the respect of those operating within healthcare systems so that our involvement helps make good things happen."
An F2F HIC

"We have heard back from families who have been successful in their insurance appeals as a result of information and guidance provided through the F2F Health Information Center. We have also been able to provide information and assistance to families so they have been successful in getting 504 plans in place for their children with chronic health conditions, when the school had previously refused a 504."
An F2F HIC

Reaching Out to Families and Professionals

Beyond providing one-to-one assistance to individual families and professionals, staff at F2F HICs and FV Network Members actively engage, educate and advocate in efforts to improve health care for children and youth with special needs. Through these efforts, F2F HICs and FV Network Members share their expertise widely and impact systems and services that support families of children and youth with special health care needs.

Listservs, Websites, Newsletters & Handouts

F2F HICs and FV Network Members reach many people through listservs, websites, newsletters, and handouts.

During the period July 2005 – June 2006:

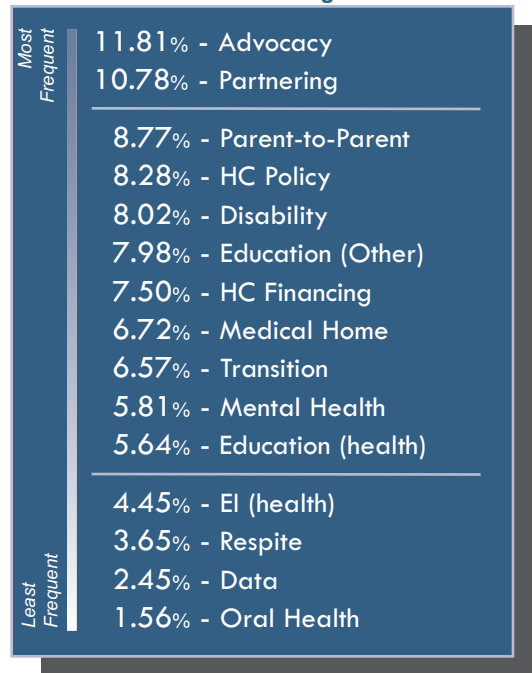
- On average, almost **150 thousand listserv participants** were provided with information from F2F HICs and FV Network Members.
- Over **27 million website hits** were recorded on websites where F2F HICs and FV Network Members post materials.
- Over **1.25 million newsletters** were distributed containing articles written by F2F HICs and FV Network Members.
- F2F HICs and FV Network Members distributed over **200 thousand handouts**, containing information about resources for families.

Meetings

Family leaders from the F2F HICs and FV Network-Member organizations reported participating in **7,260 meetings, workshops, conferences, support groups and other**

group events, attended by approximately **183,315 family members and/or professionals**, providing education, training and support to both family members and professionals.

Information Provided at Meetings



F2F HICs and FV Network Members both sponsor events and are sought out for their expertise as family leaders to participate in events. They serve on committees, conduct presentations at conferences, and develop and provide trainings to both parents and professionals. Through these meetings, F2F HICs and FV Network Members reported providing information and education on a wide range of topics, the most frequent being **advocacy and partnering**.

Data compiled in this report was contributed by the following F2F HICs and Family Voices Network Members during the period July 2005 – June 2006:

F2F HICs Funded by Maternal and Child Health Bureau: Family Voices of California Council; Florida Institute for Family Involvement; Family Voices of Illinois; Maine Parent Federation; Parent Advocacy Coalition for Educational Rights (PACER) (MN); Family Voices of Tennessee @ Tennessee Disability Coalition; Parent-to-Parent of Vermont.

F2F HICs Funded by Centers for Medicare and Medicaid Services: Alaska Family to Family Health Information Center at Stone Soup Group; Raising Special Kids, Inc.(AZ); Family Voices Colorado at CP of Colorado; FAVOR, Inc. (CT); Family Voices of Idaho/IPUL; Indiana Parent Information Network (IPIN); Family Voices of Louisiana, Inc.; Parents Place of Maryland; Mass Family Voices @ Federation for Children with Special Needs; Parents, Let's Unite for Kids (MT); Family TIES of Nevada; New Hampshire Coalition for Citizens with Disabilities; Statewide Parent Advocacy Network (NJ); Parents Reaching Out (NM); The Exceptional Children's Assistance Center (NC); Family Voices of North Dakota; Family Action Coalition Team (OR); Rhode Island Parent Information Network (RIPIN); Family Connections of SC; South Dakota Parent Connection; Texas Parent-to-Parent; Utah Family Voices Health Information Center; Family Voices of VA/Medical Home Plus; Washington PAVE; People's Advocacy Information and Resource Services (WV); Family Voices of Wisconsin.

Family Voices Network Members without F2F HIC Funding: Family Voices of Alabama; Family Voices of Arkansas; Family Voices of Delaware; Family Voices of Georgia; Family Voices of Hawaii; Family to Family - IN Transition Initiative for Young Children and Families.; Families Together, Inc (KS); Family Voices of Kentucky; Family Voices of Missouri; Family Voices of Mississippi; PTI Nebraska; Family Voices of New York; Family Voices of Ohio/Help Me Grow; Family Voices of Oklahoma; APNI, Inc. (PR).

Family Voices, Inc. is a national organization speaking on behalf of children and youth with special health care needs. Through a cooperative agreement with the Maternal and Child Health Bureau (HRSA 5-U40-06-002), Family Voices operates the National Center for Family/Professional Partnerships (NCFPP). The NCFPP, along with other smaller grants, provides technical assistance, training, and connections among F2F HICs, Family Voices Network Members and with other partnering organizations.