

# Family-to-Family Health Information Centers

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

**F2F HIC Data Summary**  
July 2004 – June 2005

## Background

Family-to-Family Health Information Centers (F2F HICs) are federally funded family-run centers established to provide information and support to families of children and youth with special health care needs (CYSHCN) and the professionals who serve them.

This report summarizes data reflecting the information and assistance provided by 21 F2F HICs during the time period July 2004 – June 2005, the second year of such analysis. This data includes 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, etc. Data is submitted quarterly by the F2F HICs to Family Voices, Inc, a national family organization that provides training and technical assistance to these F2F HICs as well as opportunities for them to work collaboratively with each other and with other family leaders throughout the country.

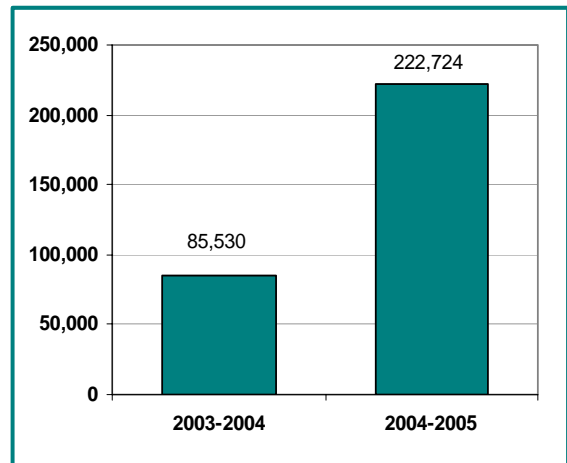
## Summary

Data reported indicate that F2F HICs are an important source of information and support for families and professionals. The number of requests for assistance from families and professionals to F2F HICs increased substantially in this second year of aggregating data. This increase is most likely due to: an increase in the number of F2F HICs who submit data; improvements in the quality of data tracking; growth in their outreach and visibility; and an increase in families/professionals seeking assistance. Sixty-one percent of requests were made by families and 39% were made by professionals during 2004-2005. In response to requests for assistance, F2F HICs provided more information about health care financing than any other topic. Of the health care financing problems reported by families, the largest increase was in problems with public health care financing programs. Through meetings, websites, listservs, newsletters, and handouts, F2F HICs reported reaching a wide variety of people with a wide range of information.

## Families and Professionals Needing Assistance

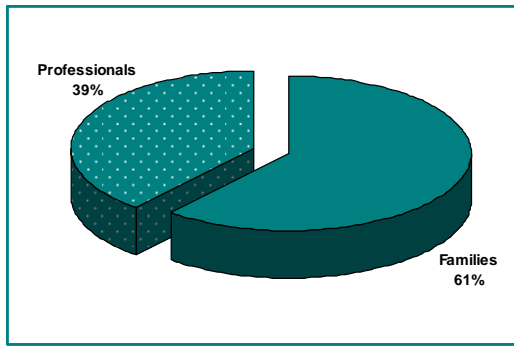
Many families need assistance finding and providing care for their children and youth with special health care needs. Professionals also seek assistance from F2F HICs in order to work more effectively with families, children and youth, and other family organizations. Charts 1 and 2 provide information on the requests for assistance made by families and professionals.

**Chart 1. Comparison of Requests for Assistance (Years 1 & 2)**



Twenty-one F2F HICs reported receiving 222,724 requests for assistance during the period July 2004 – June 2005, compared to 85,530 requests reported by 12 F2F HICs in the previous year. There was a 149% increase between the first and second year when comparing data from the 12 F2F HICs who reported in both years. This increase most likely indicates not only increased reporting capacity, but also a growth in the outreach of these F2F HICs and a wider public recognition that these centers are a place to find help. Assistance provided to families and professionals most often occurred by phone but also took place by email and through direct personal contact, such as at meetings, conferences or workshops. Many family members or professionals made contact with an F2F HIC more than once in order to obtain the assistance they needed. On average, staff at an F2F HIC was in contact with each professional or family twice in order to complete the assistance that was requested or to provide additional information.

**Chart 2. Assistance to Families and Professionals**



Both professionals and families sought assistance from F2F HICs:

- 135,517 (61%) requests for assistance were from families
- 87,207 (39%) were from professionals

Examples of requests from families included finding payment for medical care, learning about Early Intervention (EI), seeking to talk with another parent, or looking for help navigating public programs. Examples of requests from professionals included seeking a family perspective on materials, identifying parents to serve on advisory committees, looking for information to help a family find community resources, or requesting a media interview.

Staff at F2F HICs estimated that, on average, 37% of the families with whom they were involved were from underserved communities. This estimate represents a wide range of populations including those from diverse ethnic and socio-economic backgrounds and geographic settings. F2F HICs reported using a variety of methods to identify the demographics of individuals seeking assistance, including participant self-identification, census statistics, primary language spoken by families, and geographic areas served within a state.

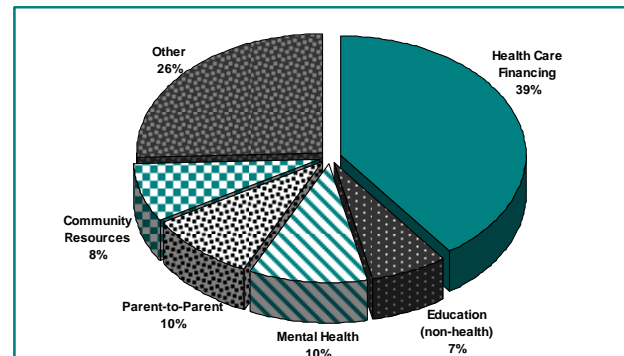
*Some exciting outcomes in our work around youth transition and leadership. . . Two of the longer standing regional youth leadership groups have youth who never imagined themselves attending college and are currently doing so and others who are seeking scholarship assistance to make it happen. (ME)*

### Information and Assistance Provided

Parents rarely have the time to prepare themselves to care for a child with special needs. Often, mothers, fathers, and other caretakers are thrown into an overwhelming world of medical

technology, insurance bureaucracy, and a social services maze when they learn that their child has a special need. Many families call an F2F HIC not knowing what they need to help themselves or their child. Staff at F2F HICs, having traveled this road themselves as parents of CYSHCN, are in the best position to listen, understand, and help. The chart below indicates some of the kinds of information and assistance that F2F HICs provided.

**Chart 3. Topics of Information Provided**



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

Information about health care financing was the most frequently reported type of assistance provided. Information about Parent-to-Parent Support, Mental Health and Community Resources were the next most frequently reported categories. Topics under "Other" included Respite, Oral Health, Transition, Partnerships, Advocacy, Medical Home, Screening and Conferences.

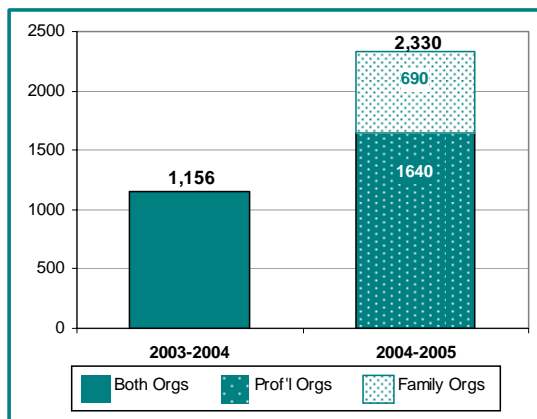
The President's New Freedom Initiative Report, "Delivering on the Promise" (March 2002)\* sets forth a goal of eliminating barriers that prevent people with disabilities from fully participating in their community. One way that F2F HICs work toward the President's goal is by providing information to families and professionals related to six performance measures (PM) of appropriate systems of health care for CYSHCN through one-to-one contacts as well as through meetings, workshops, conferences, etc. In data collected from July 2004 through June 2005, F2F HICs indicated that they provided assistance about:

- **Health Care Financing** (Medicaid, EPSDT, SCHIP, SSI, other public financing programs, related services in IEP/504/IFSP, and private insurance) in 96,091 encounters and 736 meetings (PM 4)
- **Community Services and Parent-to-Parent Support** in 42,303 encounters and 837 meetings (PM1)
- **Partnering with Professionals** in 12,741 encounters and 1,365 meetings (PM 2)
- **Medical Home** (access to care, care coordination, partnering with doctors) in 11,060 encounters and 624 meetings (PM 3)
- **EI Screening** in 7,257 encounters (PM 5)
- **Transition to Adult Services** in 4,435 encounters and 529 meetings (PM 6)

\* <http://www.hhs.gov/newfreedom/final/hhspart3.html#sol3c>

F2F HICs are often asked to review materials to provide a family perspective. These requests may solicit F2F HIC staff opinion and comments on surveys, agency reports, family-targeted materials, and other kinds of publications.

**Chart 4. Comparison of Requests to Review Materials (Years 1 & 2)**



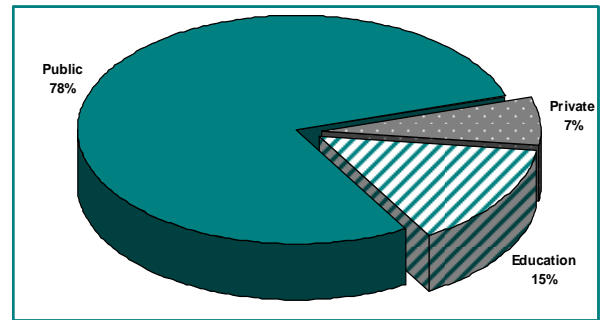
As shown in Chart 4, these requests increased from 1,156 in the first year to 2,330 in the second year. Of this latter total, 70% of these requests to review materials were from professional organizations, while 30% were from other family organizations. For the 12 F2F HICs reporting in both years this was a 39% increase.

*Families continue to fall in the gap areas due to being over the income guidelines, not knowing how to access services. There is a high need to assist the underinsured, as well as the uninsured. (ND)*

### Assistance with Health Care Financing

Adequate health care financing is a critical component of quality care for a child or youth with special needs. The chart below indicates the distribution of problems by program reported by families in obtaining financing for needed services.

**Chart 5. Problems with Health Care Financing by Program**

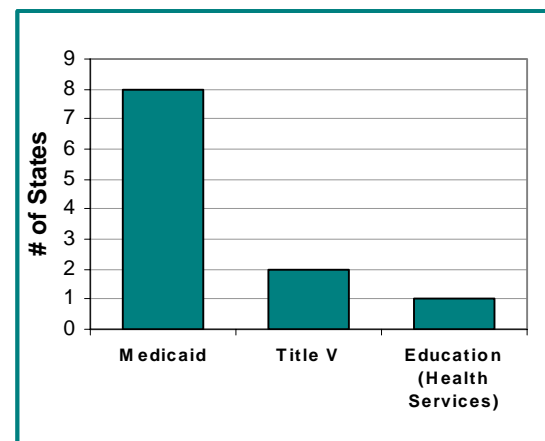


Families seeking help from F2F HICs reported nearly 39,577 problems related to health care financing.

- 78% of the problems reported (31,080) were about public financing programs, such as Medicaid, SCHIP, Title V, and SSI.
- 15% of the problems reported (5,858) were about health-related services in schools or early intervention programs.
- 7% of the problems reported (2,639) 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.

**Chart 6. Health Care Financing Programs with Most Reported Problems**



F2F HICs are developing the capacity to track family-reported problems with health care financing by program. Of the 11 F2F HICs that consistently tracked problems with health care financing by program, eight F2F HICs indicated that their most frequently reported problems were related to Medicaid; two reported the most problems were about Title V; one indicated they were about health services under an Educational Program.

## Reaching Out to Families and Professionals

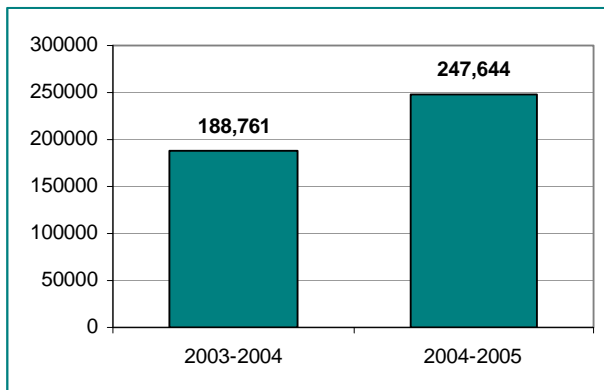


Beyond providing one-to-one assistance to individual families and professionals, staff at the F2F HICs engage and educate many people in a variety of ways about many issues. F2F HICs reported the following activities during 2004 – 2005:

### ➤ Meetings

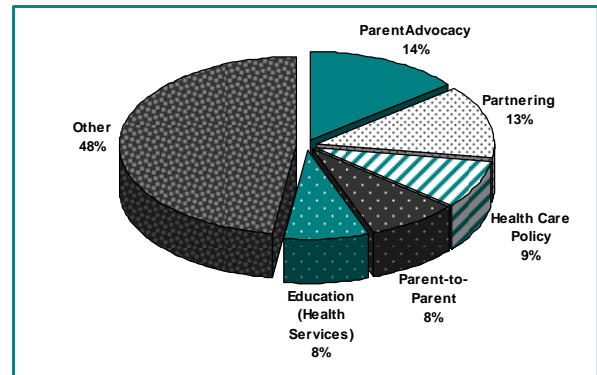
Education, training and support are provided to both family members and professionals through meetings, workshops, conferences, support groups, and other group gatherings. Staff at the F2F HICs reported participating in over **6,300 of these meetings and other group events**, attended by approximately **247,644 family members and/or professionals** providing many opportunities to reach out, educate, and collaborate with others as shown in Chart 7. Of the 12 F2F HICs who reported data in both years, there was a 21% increase in participation in these kinds of meetings and group events during 2004-2005.

**Chart 7. People Reached through Meetings (Years 1 & 2)**



F2F HICs 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. Their breadth of knowledge and experience allow them to share valuable information across a variety of topics, as shown in Chart 8.

**Chart 8. Topics of Meetings**



As shown above, the two topics of information most frequently provided at meetings related to Parent Advocacy/Leadership and Partnering with Professionals, critical skills needed by families to help them obtain and provide care for their children and youth.

### ➤ Listservs, Websites, Newsletters & Handouts

F2F HICs reach many people through mediums such as listservs, websites, newsletters, and handouts. During the period July 2004 – June 2005:

- On average, almost **18,000 listserv participants** were provided with information from F2F HICs.
- Over **13.5 million website hits** were recorded on 16 F2F HIC websites, where F2F HICs post materials.
- Over **758,000 newsletters**, containing articles written by F2F HICs were distributed.
- F2F HICs distributed over **202,000 handouts**, containing information about resources for families.



F2F HICs may be supported by funding from more than one source, including federal grants, state funds, foundation grants and fundraising. The Maternal and Child Health Bureau (MCHB) and the Centers for Medicare and Medicaid Services (CMS) provided specific funding to the following F2F HICs during the period July 2004 – June 2005:

**Funded by MCHB:** Family Voices of California Council; Florida Institute for Family Involvement; Maine Parent Federation; Parent Advocacy Coalition for Educational Rights (PACER) (Minnesota); Family Voices of Tennessee @ Tennessee Disability Coalition; Parent-to-Parent of Vermont

**Funded by CMS:** Alaska Family to Family Health Information Center at Stone Soup Group<sup>\*\*</sup>; Family Voices Colorado at CP of Colorado; The Indiana Parent Information Network, Inc; The Parent's Place of Maryland, Inc; Parents, Let's Unite for Kids (Montana); Family TIES of Nevada, Inc; Statewide Parent Advocacy Network, Inc (New Jersey); South Dakota Parent Connection; Family Voices of Wisconsin; Raising Special Kids (Arizona); The Arc of Kentucky, Inc; Family Voices of Louisiana, Inc.; Massachusetts Family Voices @ the Federation for Children with Special Needs; Exceptional Children's Assistance Center (North Carolina); Family Voices of North Dakota, Inc; Parents Reaching Out, Inc (New Mexico)<sup>\*\*</sup>; Parent to Parent of New York, Inc<sup>\*\*</sup>; Utah Family Voices; People's Advocacy Information and Resource Services (PAIRS) (West Virginia) <sup>\*\*</sup>

<sup>\*\*</sup> No data submitted to Family Voices during this reporting period