

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, 2003 through June, 2004

FAMILY  VOICES[®]

Family Voices is a national grassroots network of families and friends that advocates for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs; promotes the inclusion of all families as decision makers at all levels of health care; and supports essential partnerships between families and professionals.

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This report is based on information provided by the Family to Family Health Information Centers (F2F HICs) funded as of September, 2004. In October 2004, an additional 10 F2F HICs were funded, and subsequent reports will include information from them.

Funded by MCHB in June, 2002 for 4 years:

Family Voices of California Council www.familyvoicesofca.org
Florida Institute for Family Involvement www.fifionline.org
Maine Parent Federation www.mpf.org
Pacer Center (Minnesota) www.pacer.org/health/index.htm
Family Voices of Tennessee @ Tennessee Disability Coalition
www.tndisability.org/familyvoices
Parent to Parent of Vermont www.partoparvt.org

Funded by MCHB in May, 2003 for 1 year:

Family Voices of Iowa at ASK Resource Center
www.askresource.org/family%20voices/index.html

Funded by CMS in October, 2003 for 3 years:

Stone Soup Group (Alaska)¹ www.stonesoupgroup.org
Cerebral Palsy of Colorado www.cpcoco.org
The Indiana Parent Information Network, Inc. www.ipin.org
The Parents' Place of Maryland, Inc.¹ www.ppmmd.org
Parents, Let's Unite for Kids¹ (Montana) www.pluk.org
Family TIES of Nevada, Inc. www.familytiesnv.org
Statewide Parent Advocacy Network of NJ, Inc. www.spannj.org
South Dakota Parent Connection www.familyvoicessd.org/home.shtml
Family Voices of Wisconsin www.wfv.org/fv/

¹ No data submitted to Family Voices during this reporting period.

Background

Family to Family Health Information Centers (F2F HICs) are federally funded family-run centers established to assist families of children with special health care needs (CSHCN) to make informed choices about health care in order to promote good treatment decisions, cost-effectiveness, and improved health outcomes. In addition, F2F HICs are charged with: identifying successful delivery models, providing information on the health care needs and resources available, encouraging collaboration between families of such children and health care professionals, and providing training and guidance on their care.

Initially (June 2002), seven family-run organizations were funded as F2F HICs by the Health Resources and Services Administration (HRSA) through the Maternal and Child Health Bureau (MCHB). In October 2003, nine additional family run organizations were funded by the Centers for Medicare and Medicaid Services (CMS).

Family Voices provides training and technical assistance (TA) to the MCHB funded F2F HICs through a cooperative agreement with MCHB and to the CMS sites through a contract with the Office of Research and Sponsored Programs at Rutgers University. In this role, Family Voices provides opportunities for F2F HICs to work collaboratively with each other and with family leaders throughout the country.

Process

Family Voices has developed a variety of data tools to help F2F HICs and other family leaders document the assistance they provide to families and professionals and the outreach and partnership activities in which they engage. Each F2F HIC is requested to submit specific data quarterly. Family Voices aggregates the data

submitted and provides summary and trend analysis to individual F2F HICs, MCHB, and CMS. This documentation of reported F2F HIC activity helps to demonstrate the demand for a 'family voice' in health care policy and progress toward the development of a system of care for children and youth with special health care needs.²

Some F2F HICs are located within family agencies that operate with support from more than one funding source. They may blend funding from federal grants, state funds, foundation grants and fundraising in order to carry out their work. Other F2F HICs are newly formed and operate primarily on the federal funding they receive through their F2F HIC grant. In addition to the data summarized here by Family Voices, F2F HICs collect other information representing activities specific to their organization.



Summary

This report presents information aggregated from 13 F2F HICs and provides an early indication of the extent and importance of the activities of these critical family centers.

The data indicates that F2F HICs are steadily increasing their capacity to document what they do. Both families and professionals frequently seek expertise and assistance from F2F HICs. The most common concerns reported relate to needs for adequate health care financing and links to community resources. F2F HICs share their family perspective widely through many mediums. Specific findings are summarized in the following areas:

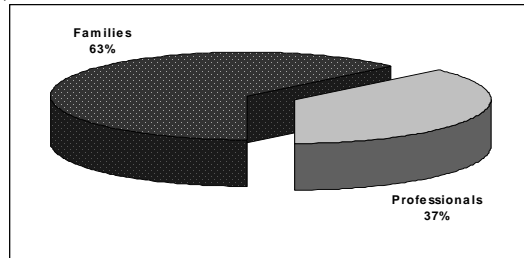
- *Families and Professionals Needing Assistance*
- *Information and Assistance Provided*
- *Help with Health Care Financing Issues*
- *Outreach to Families and Professionals*

² National Performance Measures and Goals, pg. 8

FAMILIES AND PROFESSIONALS NEEDING ASSISTANCE

Many families need assistance in finding and providing care for their children and youth with special health care needs. Professionals, too, seek assistance from family centers in order to be more effective in working with families and children. Charts 1 through 3 provide information on the requests for assistance made by families and professionals.

Chart 3. Assistance to Families and Professionals



Both professionals and families seek assistance from F2F HICs:

- 31,581 requests for assistance (37%) were from professionals
- 52,896 (63%) were from families.

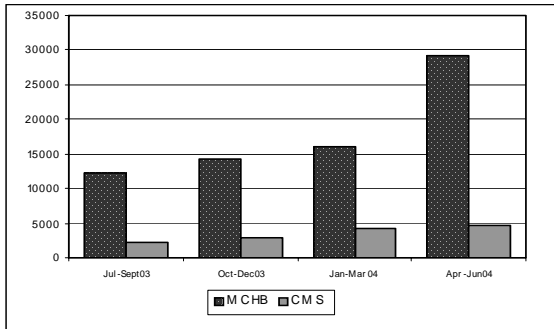
Examples of requests from families include finding payment for medical care, learning about Early Intervention (EI), seeking to talk with another parent, and navigating public programs.

Examples of requests from professionals include reviewing materials, identifying parents to serve on advisory committees, looking for information to help a family find community resources, and requesting a media interview.

Staff at F2F HICs estimated that, on average, 45% of all families with whom they have been involved in all their activities were from underserved communities. This estimate represents a wide range of populations including those from diverse socio-economic backgrounds and geographic settings. F2F HICs reported using a variety of methods to determine this outreach, including participant self-identification, census statistics, primary language, and geographic areas served within a state.

"There is a great need for information and training on cultural competence and health disparities (on the part of providers). Cultural Disparities tend to be a big issue for families in rural areas, that are low income, and that are racial/ethnic minorities. These families and their children are falling through the cracks of our health care system." (NV)

Chart 1. Requests for Assistance by Quarter

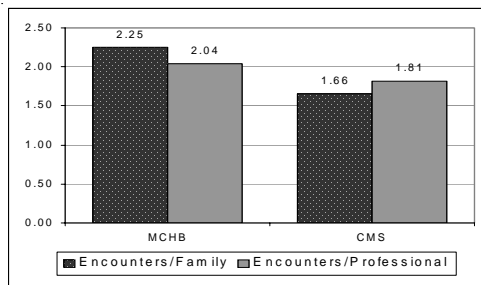


84,477 requests for assistance were received by the F2F HICs during this time period. These requests most often occur by phone, but also take place by email and through direct personal contact, such as at meetings or workshops.

Reported requests increased each quarter as the F2F HICs became more established.

The data reported reflects the fact that MCHB funded sites: are required to report this data, were provided an additional financial allocation to assist them in data collection and have an additional year's experience in operation.

Chart 2. Contacts per Individual



Because of the complexity of medical needs and health care systems, parents and professionals usually make contact with F2F HICs more than once in order to obtain the assistance they need.

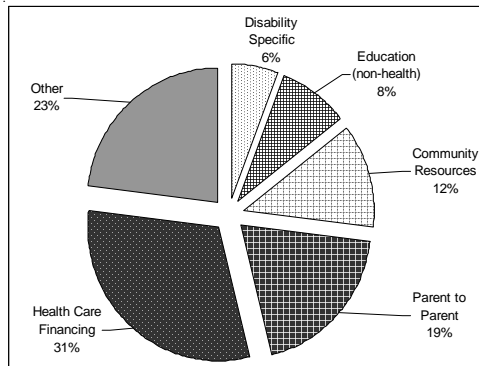
INFORMATION AND ASSISTANCE PROVIDED



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 CSHCN, are in the best position to listen, understand, and provide information. The following charts indicate some of the kinds of information and assistance F2F HICs provide.

Chart 4. Topics of Information Provided



In response to requests for assistance, staff at F2F HICs 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. Information about Parent-to-Parent support and Community Resources were the next two most frequently reported categories. Topics under "Other" include respite, oral health, transition, partnerships, advocacy, medical home, screening, mental health and conferences.

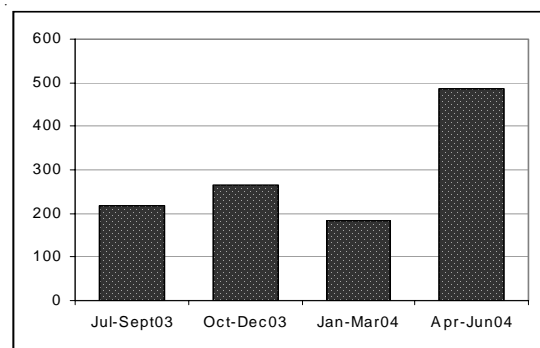
Topics of Information Related to National Performance Measures

When families or professionals contact a F2F HIC, the topics of information and assistance provided can indicate areas of family need related to many aspects of a system of care. F2F HICs provide support and information around each of the six national performance measures.²

F2F HICs reported providing information about:

- Community services and parent to parent support in 27,567 encounters (*Performance Measure 5*)
- Health Care Financing (Medicaid, EPSDT, SCHIP, SSI, other public financing programs, related services in IEP/504/IFSP, and private insurance) in 26,930 encounters (*Performance Measure 4*)
- EI Screening in 3,550 encounters (*Performance Measure 1*)
- Medical Home (access to care, care coordination, partnering with doctors) in 2,865 encounters (*Performance Measure 3*)
- Partnering with professionals in 2,318 encounters (*Performance Measure 2*)
- Transition to adult services in 1,346 encounters (*Performance Measure 6*)

Chart 5. Requests to Review Materials



F2F HICs helped to provide the family perspective and expertise in the development and review of journal articles, agency reports, surveys, materials for families and other kinds of publications in response to 1,156 requests from professionals and family organizations.

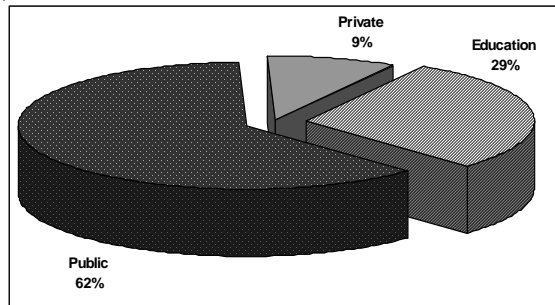
"FL is not only in the process of implementing draconian changes in its T21 Program as the result of legislation, but we are also in the process of revising and overhauling the state Medicaid program... We not only have an increase in calls and requests from families AND professionals for assistance, but we are now involved in several meetings a week ..."

² National Performance Measures and Goals, pg. 8

Helping with Health Care Financing Issues

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

Chart 6. Problems with Health Care Financing by Program



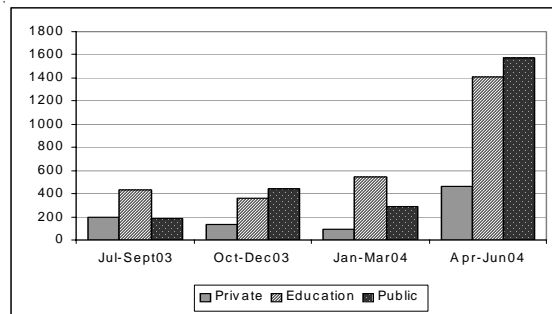
Families seeking help from F2F HICs reported nearly 10,000 problems related to health care financing.

- 62% of the problems reported (5,893) were about public financing programs, such as Medicaid, SCHIP, Title V, and SSI.
- 29% of the problems reported (2,742) were about health-related services in school programs (IEP, 504 plan or IFSP).
- Just under 10% of the problems reported (882) were related to private insurance.



Examples of reported problems with health care financing include needed services limited in amount or duration, referrals to specialists denied, denials of eligibility to programs, providers not available, and waiting lists.

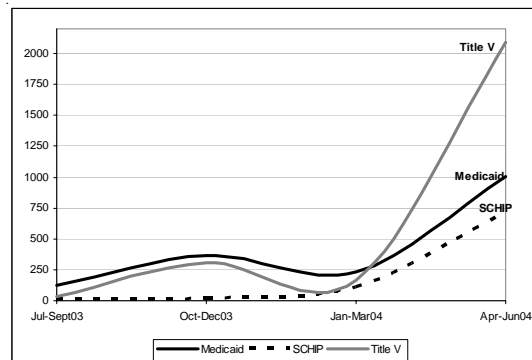
Chart 7. Problems with Health Care Financing by Quarter



The number of reported health care financing problems increased over the four quarters.

This increase is likely due to both a greater capacity of F2F HICs to track problems and an increase in problems experienced by families.

Chart 8. Problems with Medicaid, SCHIP, Title V by Quarter



Tracking changes in the number of reported problems by program can alert F2F HICs to changes in systems that impact families.

"The families that are reporting problems with Medicaid are reporting a number of issues. . . We are finding that families are being denied a number of services . . . when they would have been provided those services a year ago. . . Lastly, children who would typically (have) been approved for Katie Beckett a year ago are being denied in their applications. Overall, there appears to be a trend towards a reduction in both coverage and services through Medicaid." (VT)

"Strict income guidelines placed on most services make working poor and middle income families ineligible for services, which places a great hardship on the family. It is tragic that we have actually taken a few telephone calls from these low to middle income families requesting information on residential programs or institutions to place their child in because they either can not afford to provide for their child at home, or they do not have the physical or emotional supports to maintain their child at home." (TN)

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.

NEWSLETTERS



Over **1.5 million newsletters**, containing articles written by F2F HICs were distributed from July, 2003 through June, 2004. News-

letters published by the F2F HICs often include information about resources, upcoming events, family stories, state and national issues, book reviews, parent to parent support, and other information. Staff frequently contribute articles to other parent center newsletters, state agency publications, and regional newspapers.

HANDOUTS

F2F HICs distributed over **460,000 handouts** from July, 2003 through June, 2004.

Handout materials may be developed specifically by the F2F HICs, or gathered from other sources.

Handouts provide information about programs and resources, and materials for families such as how to understand and take part in a child's health care, how to advocate for quality health care or how to partner with professionals.



LISTSERVS

F2F HICs reached, on average, over **9,025 people** with information through e-mail listservs. Listservs provide opportunities to share news, pose questions on finding services, and convenient ways to disseminate information quickly to a large and interested group.

"We sent out statewide action alerts regarding the proposed Medicaid cuts which didn't happen due to efforts of various state/national groups. . . Media contacts included being interviewed for a new care giving book covering the lifespan, appearing multiple times on cable regarding special education issues, and various blurbs in the local newspaper." (NJ)

WEBSITES

Over **5.8 million hits** were recorded on nine F2F HIC websites. In some cases websites are developed and maintained by the F2F HICs and in other instances the F2F HICs share web presence with another family organization. Many provide multi language materials, and materials for diverse communities.



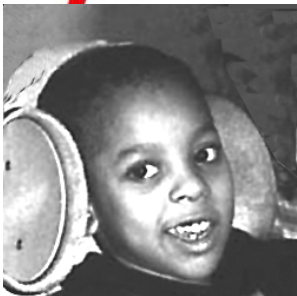
MEETINGS

Staff at the F2F HICs participated in over **4,250 meetings, workshops, conferences, and other group events**. These meetings were attended by approximately **189,000 family members and/or professionals** providing many opportunities for staff to reach out, educate, and collaborate with others. F2F HICs both sponsor events and are sought out for their expertise as family leaders to participate in events. They serve on on-going committees, present at conferences, and develop and provide trainings to both parents and professionals. Examples include Medicaid or Title V Advisory Committees, trainings on advocacy, and conferences on leadership development.

Beginning April, 2004, data was collected on the topic areas of the meetings, workshops, etc. The most frequently presented and discussed topic noted by the F2F HICs was on **"helping parents to collaborate and partner with professionals"**, followed by **"helping parents to develop advocacy and leadership skills"** and **"disability specific information"**.

F2F HICs reported spending over **8,000 volunteer or in-kind hours** from July, 2003 through June, 2004 assisting families and professionals.

In the President's New Freedom Initiative report, "Delivering on the Promise" (March, 2002), HRSA is charged with developing and implementing plans to achieve appropriate community-based systems for children and youth with special health care needs and their families, also a Healthy People 2010 objective. The Maternal and Child Health Bureau provides guidance to their State Title V Block Grant Programs and grantees on methods to achieve this mandate through the following six national performance measures and goals related to CYSHCN.



- 1. To assure early screening and early intervention for all children with special health care needs.*
- 2. To increase the number of families with CSHCN who partner in decision making and are satisfied with the services they receive.*
- 3. To increase the number of children with special health care needs who have a medical home.*
- 4. To increase the percent of children with special health care needs, age 0-18, with adequate insurance coverage for all the services they need.*
- 5. To increase the number of families with CSHCN who have access to easy-to-use community-based service systems.*
- 6. To increase the percent of children with special health care needs, age 0 to 18, who have received the services necessary to transition to adult health care, work, and independence.*

