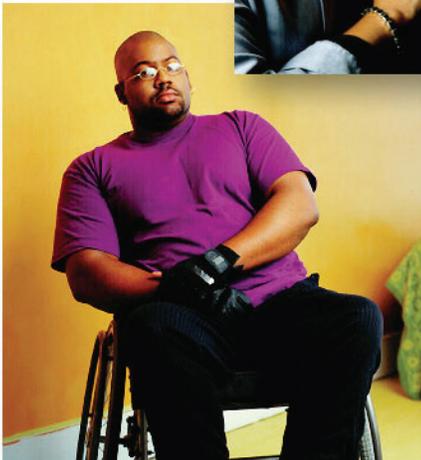


Real Choice Systems Change Grant Program

Activities and Accomplishments of the Family to Family Health Care Information and Education Centers



U.S. Department of Health and Human Services
Centers for Medicare & Medicaid Services

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**Activities and Accomplishments of the
Family to Family Health Care Information and Education
Center Grantees**

Angela M. Greene, M.S.

Edith G. Walsh, Ph.D.

Janet O’Keeffe, Dr.P.H.

Elizabeth Koetse, B.A.

Federal Project Officer: MaryBeth Ribar

RTI International*

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Overview

This paper is one in a series addressing major topic areas in the Systems Change for Community Living Grants Program. It describes the activities of 19 Grantees who received grant funding in fiscal years 2003 and 2004 from the Centers for Medicare and Medicaid Services (CMS), and six Grantees funded in fiscal year 2002 by the Maternal and Child Health Bureau (MCHB)/Health Resources and Services Administration (HRSA). The purpose of the grants is to support the development of Family to Family Health Information Centers to assist families of children with special health care needs to obtain the wide range of services and supports they need.

This paper describes grant activities, implementation challenges, and accomplishments. Its primary purpose is to provide information that states and stakeholders will find useful when planning or implementing similar initiatives.

Children and youth with special health care needs (CYSHCN) are individuals under the age of 18 “who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” Their needs range from early and ongoing screening, diagnosis, and routine treatment and monitoring to extensive ongoing specialty care, medical equipment, therapies, and long-term services and supports. Nationally, 12.8 percent of children (9.4 million children) have a special health care need, affecting one in five U.S. households with children.

Parents often lack knowledge about the wide range of services and supports for CYSHCN and have little experience dealing with the health and long-term care systems and the health insurance bureaucracy. Family to Family Health Information Centers (*hereafter*, FHICs) provide a critically important service by educating parents about available services and helping them navigate complex systems and bureaucracies. They also help families make informed choices about health care in order to improve health and functional outcomes. FHICs also promote the philosophy of family-centered care and individual- and family-directed supports through education and training initiatives targeted to health care and other providers.

In 2001, President Bush announced the New Freedom Initiative to promote community living for persons with disabilities and expanded this initiative through Executive Order 13217 by instructing federal agencies to work together to eliminate barriers to community living. In response, the Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB) and the Centers for Medicare and Medicaid Services (CMS) have established grant programs to help develop FHICs and have awarded approximately \$7 million since 2002.

Grantee Activities

Grantees are providing many services to the families of CYSHCN and the health, long-term care, and other professionals who serve them.

Information and Referral

Grant staff provide extensive one-on-one information and referral services to both families and professionals. Families often request help to identify information about (1) available health resources, (2) their children's medical conditions, (3) private health insurance, and (4) publicly funded services. They also seek assistance with the application process for public programs such as Medicaid, Early Intervention, the State Children's Health Insurance Program, and the Supplemental Security Income (SSI) Program. Health care professionals also seek information from FHICs, often about the Medicaid program.

Development and Dissemination of Information Materials

Grantees have developed a range of print and Web-based materials including newsletters, brochures, information packets, fact sheets, resource notebooks, and care notebooks to provide a system to organize information about a child's medical history, daily activities, appointments, and medical expenses. To meet the needs of non-English speaking families, many FHICs translate their materials into languages common in their states, such as Spanish, Portuguese, and Chinese.

To address the statewide need for information, FHICs are disseminating materials in various formats including CD-ROMS and DVDs, as well as through the Internet. Web sites and electronic mailing lists are particularly useful in reaching families who have computer access in rural and frontier areas. Partner organizations, including other non-profit and community-based organizations, state chapters of the American Academy of Pediatrics, the Title V program, and individual pediatricians and case managers also assist with dissemination by printing and distributing FHIC materials.

Education Initiatives

FHICs provide in-depth education in workshops and at conferences and facilitate family participation by providing modest subsidies for travel expenses and respite care. Sample topics covered are Medicaid eligibility and benefits and transitioning from child health and support services to the adult service system. To serve families who cannot attend in person, many FHICs use technology such as Web-based conferences, teleconferences, and video-conferences. To reach the greatest number of families possible, they also employ train-the-trainer educational approaches, so those participating can share what they've learned with other families in their communities.

FHICs also provide programs for health professionals, including physicians, nurses, and social workers, and for medical and nursing students. In addition to offering workshops and seminars (some of which are approved for continuing education credits), FHICs have developed opportunities for family members to directly educate professionals. For example, they arrange for parents to serve on health care committees, to speak to university classes, and to meet individually with medical and nursing students, social workers, and pediatric residents.

Promoting Family-Centered Care and Medical Homes

FHICs are working to improve the quality of medical care for CYSHCN by working with individual medical practices to promote family-centered, culturally competent care and the development of medical homes and by serving as a resource for information about services. This work helps to increase the number of families with access to a primary care practice in which the clinicians help to coordinate specialty care and home and community services. The work also helps to assure that the care provided is based on respectful family-professional partnerships that involve parents in decision making and respects their preferences.

Disaster Preparedness

FHICs vary in their involvement in disaster preparedness and response. Their activities include (1) outreach to identify and assist evacuated families, (2) disseminating information about disaster preparedness for CYSHCN, (3) partnering with local emergency medical service organizations, and (4) participating in local, state, and national initiatives to ensure that the evacuation and relief needs of CYSHCN are considered in disaster planning.

Improving Programs and Informing Policies

Policymakers and program administrators may not understand how specific policies and program provisions affect service delivery. Consequently, educating policymakers and other stakeholders about the needs of CYSHCN and the challenges families face is critical to assuring the quality and timely receipt of services.

Working to improve the quality of care through Medical Home and Family-Centered Care initiatives is one example of FHICs' work to improve the system. Many FHICs also engage in activities to educate policymakers about program and policy issues that are important to families of CYSHCN and to provide parents with the opportunity and training needed to play a role in the policymaking process. Federal sponsorship of the FHICs helps them to play a meaningful role in these processes by increasing their visibility and perceived legitimacy.

Developing Partnerships

Effective partnerships are critical to FHICs' ability to achieve their goals, to avoid duplication of efforts, and to sustain their work. Most FHICs are partnering with other nonprofit and community-based organizations and their states' Title V programs to provide information and referral services or to assure that the family perspective is represented in policy decisions. FHICs also collaborate with state and local agencies and programs, managed care organizations, hospitals and medical practices, tribal organizations, universities, and public school districts.

Challenges

FHICs face a number of challenges, particularly given their modest grant funding, the high demand for their services, and the limitations of the health, long-term care, and social service systems that support CYSHCN.

Inadequate Staffing

FHICs rely to a great extent on staff who are parents of CYSHCN and on volunteers. As the demand for their services increases, additional funding will be needed to assure adequate staffing. FHICs are using various approaches to address staffing shortages, such as recruiting more volunteers, sharing staff with other organizations, and using train-the-trainer educational approaches.

Inadequate Resources to Serve Diverse Groups

While FHICs are using the Internet and translator and interpreter services, and are partnering with other groups to serve a diverse array of families, Grantees identified several groups whose unique needs present challenges due to lack of funding: (1) those with limited English skills or literacy, (2) geographically isolated families, (3) military families who need information about the armed forces health insurance program and assistance finding resources when relocated, (4) Native American families on reservations, and (5) minorities and disadvantaged groups, including families with low educational levels.

Obstacles to Parent Participation

Despite FHICs' commitment to maximizing parent participation, financial and time constraints limit some parents' ability to attend trainings, to be members of advisory boards and committees, and to volunteer to help other families. Although FHICs support their participation by using grant and other funds to pay for some respite and travel expenses, these constraints continue to impede parental involvement, particularly among those with preschool children.

Data Collection

Data collection can provide valuable information for the FHICs' own planning and evaluation needs and can help them communicate their needs to state agencies and legislatures. Challenges to data collection include the need to (1) obtain consensus about data to collect, (2) provide training to support data collection activities, (3) coordinate with the reporting requirement of multiple funders, and (4) obtain uniform data from multiple sites often staffed by volunteer parents. To the extent that FHICs' ability to collect data is dependent on current grant funding, it is unlikely to continue when the grant ends.

Sustainability

The grants are intended to provide seed money to help establish an ongoing FHIC in states receiving the grants. Grantees need to develop plans to sustain their work when the grants end and are pursuing several strategies to do so. Many are applying for new grants, alone or in partnership with other organizations. One FHIC is investigating the option of becoming

a Medicaid provider of family support services. Some are contracting with managed care organizations to provide information services to their members for a fee, and others are generating income by offering education that provides continuing education credits for health care professionals.

Family Voices, the FHIC Technical Assistance provider, is assisting the Grantees by providing sustainability tool kits and organizing conference calls to discuss approaches and options. Many of the stakeholders we interviewed stressed the importance of the work FHICs are doing, but acknowledged the lack of resources to continue this work.

Conclusions

As evidenced by the Survey of Children with Special Health Care Needs and the experiences communicated by families, community partners, and other stakeholders, FHICs are performing a vital service for families with CYSHCN and the professionals who serve them. In increasing numbers, families are turning to the FHICs for information and guidance about the maze of health, long-term care, and social service programs—both public and private. Between July 2004 and June 2005, 21 FHICs received over 220,000 calls for assistance, about 150,000 from families and 70,000 from professionals. Although funding levels limit their reach, the FHICs are clearly committed to meeting the needs of diverse populations throughout the state, including minority families and parents in rural and frontier areas.

The accomplishments of these Grantees are impressive, particularly in light of their modest grant funding. They have creatively extended this funding through the formation of strategic partnerships, the use of technology, by recruiting volunteers, and to some extent, by developing community and regional networks throughout their states.

Through their work to promote family-centered, culturally competent, and linguistically appropriate care and medical homes for CYSHCN, FHICs are contributing to improvements in the quality of health care. They are also playing an important role in reshaping local and state policies and practices regarding care for CYSHCN. By helping families to provide a consumer perspective on program and policy issues, FHICs enable states to develop more effective ways to assist families with CYSHCN.

CMS and HRSA have developed an effective grant program supported by technical assistance and opportunities for FHICs to share information and make connections across their national network.

The ultimate goal for FHICs is to improve health and functional outcomes for CYSHCN. To the extent families understand what is available for their children and how to use existing services effectively, outcomes for their children will improve. The benefits of these outcomes go well beyond the children and their families. Children whose outpatient needs are met and whose parents are able to meet their daily care needs are less likely to require hospital or emergency room care. Children who obtain home and community long-term care services are less likely to need costly institutional care.

Congress has recognized the value of these organizations by authorizing funds to establish FHICs in every state. However the grants are time limited and not intended to provide ongoing support. These highly effective organizations require a stable source of funding to sustain outreach and referral services, information dissemination, and education and training initiatives.

Section 1 Introduction

Children and youth with special health care needs (CYSHCN) require a wide range of health, long-term care, social, and educational services and supports. Especially important are health services, upon which some children depend, literally, for their lives. Health services for CYSHCN are provided by multiple private and publicly funded entities, which are often neither linked nor coordinated. Learning about and navigating the health and long-term care systems is a time-consuming process that many families find daunting. Historically, parents have obtained information about these systems through informal parent networks. Under this model, parents with knowledge and experience give advice and provide direction to other parents.

Over the past several years, initiatives have been undertaken to provide information through more formal mechanisms, with the goal of reaching more families than is possible with informal networks. In 1989, the federal government charged the Title V State Programs for CYSHCN to provide leadership in developing formal systems to insure that CYSHCN and their families have timely access to appropriate and adequate services. Through this block grant, states engage in system-wide efforts to enhance the quality of care available to CYSHCN and to provide direct services to individual children meeting the state's financial and diagnostic eligibility criteria. Several discretionary demonstration grant programs have developed methods to help families learn about the health and long term care systems, such as the Federation for Children with Special Needs, the Family Voices Network, and the early Medical Home and Integrated Services and Systems grants. However, it has been difficult to move from demonstration to full implementation.

In FY 2002, HRSA issued a grant solicitation to support the development of a national network of Family to Family Health Education and Information Centers for families of CYSHCN, developed and operated by families. These FHICs are required to provide information to families that (1) increases access to and utilization of coordinated care with a medical home, (2) helps families to obtain adequate private and/or public insurance, (3) educates families about early and continuous screening and intervention services, (4) increases access to organized and easily accessible service networks, (5) increases opportunities for families to be partners in decision making at all levels, and (6) increases access to and utilization of services for youth transitioning to adulthood.¹ HRSA's goal is to promote a community-based system of services that is family centered, comprehensive, coordinated, and culturally competent.

In accordance with President Bush's instructions to federal agencies to work together to eliminate barriers to community living for people with disabilities of all ages, when HRSA was not able to issue additional grants due to funding limitations, CMS offered grant funding

for Family to Family Health Care Information and Education Centers in 2003 and 2004. CMS issued the grant solicitation under the Systems Change for Community Living Grants Program.

The purpose of the CMS grants is to support the development of comprehensive health information centers providing parents of CYSHCN with information about health care and health care financing. Non-profit organizations were awarded grants to establish statewide family-run centers that provide education and training opportunities; to develop and disseminate information about health care and home and community services to families and providers; to collaborate with existing Centers to benefit CYSHCN; and to promote the philosophy of individual and family directed supports.²

While the specific objectives of the CMS and HRSA grants differ somewhat, they share the same goal of providing information and educational opportunities to assist families of CYSHCN to make informed choices about health care in order to improve health outcomes. The grants are also intended to promote the philosophy of family-centered care and individual- and family-directed supports. Therefore, this report jointly describes the activities and accomplishments of the Real Choice Systems Change Grantees and the HRSA Grantees.

The primary purpose of the FHICs is to assist families of CYSHCN to make informed choices about health care in order to promote improved health outcomes. FHICs also promote the philosophy of family-centered care and individual- and family-directed supports. In addition, the HRSA-funded Grantees are required to collect data about services provided to families.³

Since 2002, the two agencies have awarded approximately \$7 million to organizations in 36 states to establish FHICs. HRSA will award additional grants in the spring of 2006. Additionally, Congress, under the Deficit Reduction Act of 2005, authorized and appropriated additional funding to HRSA to establish new FHICs, with the goal of having one in every state by 2009. The Family Opportunity Act of 2005 was enacted on February 8, 2006 in response to the Deficit Reduction Act of 2005. In part, it amends Title V of the Social Security Act and provides appropriations for the Maternal and Child Health Bureau, Division for Services for Children with Special Health Care Needs to develop FHICs in each of the 50 states. These FHICs are mandated to be state-based and family-run, and to provide technical assistance and peer support to families of CYSHCN. They are also charged with developing partnerships with organizations serving these children and with monitoring the progress of programs responsible for payment and direct services to this population through a statewide data collection system.⁴

Nonprofit organizations whose mission includes the provision of services to families of CYSHCN are the recipients of FHIC grants. All had experience working with families prior to

the grant award and several serve as the Parent Training and Information Center (PTI) in their respective states or as Parent to Parent organizations. As PTIs, these organizations have experience providing information and assistance to families and professionals to increase parental involvement in meeting children's educational needs. Several also have experience providing limited information about health care and health insurance to families, an activity funded through other sources. Many Grantees are large organizations with well-established infrastructures and have been in existence for more than 20 years. For these Grantees, FHIC grant funding provides coverage for one or two staff members to specialize in health information. A few Grantee organizations were newly created as a result of the grant award. All of these organizations are run by or have board members who are parents of CYSHCN. Appendix A lists the organization within each state that received grant funding, the organization Web site address, the year of award, and the source and amount of grant funding. In addition to serving families with minor children, some also serve adult children being cared for by their parents and adults with disabilities.

Technical Assistance for Grantees

To assist grant implementation, CMS and HRSA are funding technical assistance (TA) for the Grantees.⁵ The technical assistance provider, Family Voices, is a national grassroots network of families who advocate for health care services that are family centered, community based, and culturally sensitive for all CYSHCN.

Family Voices provides a wide range of TA, including helping Grantees locate information on specialized topics, providing opportunities for FHICs to network and to share materials and ideas, and providing technical information through teleconferences and electronic mailing lists on a wide range of subjects (e.g., cultural competency, working with Title V agencies, and sustainability). CMS also provides the opportunity for Grantees to share knowledge, for example, through teleconferences on developing parent networks, and to develop partnerships with potential collaborators such as the Aging Disability and Resource Centers and Children's Hospice International. Networking, partnering, and collaborating provide opportunities for Grantees to gain important knowledge and skills and help to assure that limited funds are not spent "re-inventing wheels" and duplicating efforts.

Methods

We used a variety of qualitative research methods to collect the information in this report. We first reviewed the CMS and HRSA grant solicitations, Grantees' applications, compendium forms, and Grantee's semi-annual reports.⁶ We then conducted in-depth interviews with six Grantees (two funded by HRSA and four funded by CMS), and held a series of group conference calls in which 18 Grantees participated. We also interviewed family members who had received services from FHICs, as well as stakeholders, including Title V staff, health and social service professionals, and partner organizations. Finally, we

interviewed technical assistance providers and consulted with the CMS and HRSA project officers responsible for administering the grant programs.

Interview notes were e-mailed to Grantees, family members, and stakeholders to review for accuracy. We also communicated with Grantees regarding specific topics via e-mail. Unless otherwise noted, the content of this report is based on these data sources. In some instances, we have edited quotations for brevity.

Limitations

This report relies heavily on in-depth interviews with a few Grantees and some of their partners, clients, and other stakeholders. While we invited all the HRSA and CMS-funded Grantees to participate in group discussions, not all were able to attend and the information collected was less detailed than that obtained through individual interviews. As a result, this report may cover neither the full range of activities and partnerships undertaken by the FHICs nor all of the challenges they experienced.

We asked Grantees to report on activities that can be directly attributed to the grant program. However, because many of the organizations maximize their resources by blending grant funding with other funds, or use the money to supplement or extend activities already underway, it is sometimes difficult to clearly identify the precise contribution of the HRSA and CMS funds. Nonetheless, all Grantees we interviewed reported that the grant funding was essential to their mission and had allowed them to undertake activities that would otherwise not have been possible. However, the line is not always clear and some activities reported in this paper reflect the synergy that can come from blending multiple funding sources.

Organization of the Paper

Section 2 provides brief background information about children and youth with special health care needs as well as the major publicly funded programs that serve them. This information provides the context for understanding Grantees' initiatives.

Section 3 describes Grantees' activities in several areas including (1) information and referral services for parents and professionals, (2) resource development and dissemination, (3) education initiatives, (4) promoting family-centered medical care and medical homes, (5) disaster preparedness, (6) improving programs and informing policies, and (7) developing partnerships.

Section 4 describes the challenges Grantees have faced in implementing their initiatives, and Section 5 presents our conclusions.

Section 2 Background

Children and youth with special health care needs (CYSHCN) are individuals under the age of 18 “who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” Their medical needs range from early and continuous screening, diagnosis, and routine treatment and monitoring to extensive ongoing specialty care, medical equipment, nutritional supplements, therapies, care coordination, and long-term services and supports. CYSHCN have a wide array of conditions, including developmental delays, cerebral palsy, behavioral problems, and asthma, and are often affected by more than one condition. The extent of their needs is reflected in the wide range of services used by CYSHCN and their families. See Box 1 for more information about the types and range of services that CYSHCN may need.

Box 1. Types of Services Used by CYSHCN and their Families

- Primary and Specialty Care
- Preventive Health Care and Counseling
- EPSDT (Early & Periodic Screening, Diagnosis, and Treatment)
- Emergency Medical Care
- Inpatient and Outpatient Hospital Services
- Laboratory and Radiology Services
- Prescription Medications
- Audiology Services and Hearing Aids
- Inpatient Rehabilitation
- Habilitation Services (including supported employment and educational services)
- Case Management
- Care Coordination Services
- Vision Services and Appliances
- Durable Medical Equipment (e.g., hospital beds, air mattresses, oxygen, walkers, wheelchairs)
- Organ Transplants
- Dental Services
- Mental Health Services
- Home Health Services
- Hospice Services
- Transportation Services
- Assistive Technology (communication tools)
- Therapy Services (physical, occupational, speech)
- Transition Services
- Respite Services

In 2002, the Department of Health and Human Services completed a survey of children with special health care needs,⁷ which provides national and state prevalence rates of CYSHCN, their characteristics, and information about their health care and health insurance status. See Exhibit 1 for selected findings from the survey. Nationally, 12.8 percent of children (9.4 million children) have a special health care need, affecting one in five U.S. households with children. These children vary greatly in their medical conditions and the impact of those conditions on their daily lives, ranging from 39 percent whose conditions do not affect their daily activities to 23 percent whose conditions greatly affect their daily activities.

As indicated in Exhibit 1, most CYSHCN have insurance coverage. Two-thirds are covered solely by private or employer-based insurance, 22 percent by public insurance such as Medicaid and SCHIP, and about 8 percent are covered by both public and private insurance. While only 5 percent were uninsured at the time of the survey, 11 percent were uninsured at some time during the previous year. However, children in low income families, black children, and Hispanic children were substantially more likely to be uninsured (*not shown in exhibit*).

While many health care services are covered by private health insurance plans, benefit limits, such as caps on outpatient therapies, may prevent children from receiving needed services. Close to a fifth of those with insurance reported having an unmet need for specific health care services, including access to specialists and medical equipment. Almost a quarter report having an unmet need for respite care, genetic counseling, or mental health services. Overall, about one-third of those with health insurance reported unaffordable charges or inadequate access to needed providers or benefits. Although most report having a usual source of care, about a third of parents report care to be lacking in one or more component of family-centered care, for example, not providing adequate information or not listening to the family's concerns. Low income, black, and Hispanic families also report higher levels of unmet need in these areas.

CYSHCN can have a major impact on the financial status and daily lives of their families, depending on the severity of their condition. About a fifth of families with CYSHCN experience financial problems related to their child's health needs, and almost a third report having to reduce work hours or stop working altogether to care for their children.

Exhibit 1. Characteristics of Children and Youth with Special Health Care Needs in the United States

Characteristics	Percentage
Child Health	
Health conditions consistently and often greatly affect daily activities	23.2
Eleven or more days absent from school due to illness	15.8
Health Insurance Coverage	
Without insurance at some point during the past year	11.6
Currently uninsured	5.2
Currently insured with coverage that is not adequate	33.8
Access to Care	
One or more unmet need for specific health care services (e.g., dental care, specialists, and rehabilitation therapies)	17.7
Families needed but did not get respite care, genetic counseling, and/or mental health services	23.1
Needed specialty care but had problems getting a referral	21.9
Without a usual source of care (or rely on the emergency room)	9.3
Without a personal doctor or nurse	11.0
Family-Centered Care	
Without family-centered care	33.2
Impact on Family	
Families paid \$1,000 or more in medical expenses per year	11.2
Families experienced financial problems due to child's health needs	20.9
Families spent 11 or more hours per week providing and/or coordinating health care for child	13.5
Child's health needs caused family members to cut back or stop working	29.8

Source: 2001 National Survey of Children with Special Health Care Needs

Nonprofit and Public Programs for Children and Youth with Special Health Care Needs

Families of children with special health care needs must learn to navigate a complex and sometimes bewildering array of systems that address their children's health, therapeutic, educational, and social service needs.⁸ These systems include numerous programs and services such as (1) early intervention, health, and rehabilitative services provided under Title V; (2) special education services mandated by the Individuals with Disabilities Education Act; (3) Supplemental Security Income (SSI) program; and (4) case management and therapeutic services provided by non-profit organizations like the March of Dimes, United Cerebral Palsy, and Easter Seals. See Box 2 for examples of the major programs that serve CYSHCN.

Each system of care has its own eligibility criteria, regulations, and payment structures. To the extent that boundaries between systems are unclear, families can find themselves in a "no care zone." This can happen, for example, when a managed care health plan and the special education system argue about which of them should pay for an assistive device or a rehabilitation therapy.⁹ Eligibility for some state services is often limited to children with specific qualifying diagnoses or conditions, which can leave some children with medical needs ineligible for services.

Challenges Facing Families of Children and Youth with Special Health Care Needs and the Role of FHICs in Addressing Them

Parents of CYSHCN face many challenges, particularly a lack of knowledge about the wide range of services and supports that may be available for their children, both through private insurance and the non-profit and publicly funded programs mentioned above. Additionally, most have little experience dealing with the health and long-term care systems and the health insurance bureaucracy. The medical and social service providers families encounter often have

*"My son receives specialty medical care, rehabilitation therapies, and medical equipment like a wheelchair through California Children's Services. Medicaid pays for some of his equipment, and nursing services and for help at home through the In-Home Support Services program (which allows his mother to work). To some extent, his services are coordinated by the Regional Coordination Center, which is only available to children with selected diagnoses. He qualifies through his developmental delays; he would not qualify based only on his complex medical needs. He also receives services from the Foundation for the Junior Blind, communication therapy through the school district, and an annual multidisciplinary medical evaluation at the Children's Hospital of Los Angeles Spina Bifida Center."
—Parent*

*"Families of children with chronic or acute health conditions are desperate for assistance in securing medical insurance that provides effective and sufficient coverage; understanding the complexities of their insurance coverage, processes, terminology, and advocacy strategies; building positive relationships with medical providers; dealing with the special stresses of parenting children with special health care needs; and finding others to talk to who have shared similar experiences and who can provide emotional support and resource information."
—FHIC Director*

Box 2. Major Programs that Serve Children and Youth With Special Health Care Needs.

Medicaid is a jointly funded federal-state program that provides a wide range of health, rehabilitative, and long-term care services either as a child's sole insurance or as a secondary payer supplementing private insurance. Eligibility is based on family income and assets, although children with severe disabilities can qualify through special waivers without counting their parents' income and assets. Federal regulations mandate a set of core services and each state determines which optional services to cover. Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) is available to all Medicaid-covered children and states are required to provide any service prescribed for a child through this program whether or not it is covered under the state plan.

State Children's Health Insurance Program (SCHIP) is a partnership between the federal and state governments that provides health coverage to uninsured children whose families earn too much to qualify for Medicaid but too little to afford private coverage. The federal government establishes general guidelines for the administration of SCHIP benefits. However, specific eligibility requirements to receive SCHIP benefits, as well as the type and scope of services provided, are determined by each state.

Early Intervention, mandated under Part C of the federal Individual with Disabilities Education Act (IDEA), serves infants and toddlers with developmental or physical delays by providing assessment, care planning, and service coordination. Many of the services, for example speech, physical, and occupational therapy, are provided by independent organizations (nonprofit or for profit) and some may be paid for by the family's health insurance (private, Medicaid, or Indian Health Services). States can establish sliding fee scales using state funds to supplement insurance coverage and to extend early intervention services to children at risk. Services end when children reach their third birthday.

Maternal Child Health Services Block Grant (Title V) supports programs for CYSHCN to facilitate the development of family-centered, community-based, coordinated systems of care. These efforts are system focused, build upon partnerships with other agencies, communities, and families, and are geared to improving the quality and responsiveness of the overall health care system for CYSHCN and their families and caregivers. Title V programs also provide direct health services to children and states have the authority to determine the financial and diagnostic eligibility criteria and which services to provide, in part to enable them to address gaps in their health care systems.

continued

Box 2. Major Programs that Serve Children and Youth With Special Health Care Needs—Continued

Administration on Developmental Disabilities, within the US Department of Health and Human Services, funds several grant programs that serve eligible CYSHCN. *State Councils on Developmental Disabilities* pursue systems change, capacity building, and advocacy activities. *Protection and Advocacy* systems protect the legal and human rights of individuals with disabilities. *University Centers for Excellence in Developmental Disabilities (UCEDDs)* provide interdisciplinary training, community service activities, and dissemination of information and research findings.

Special Education, also mandated by IDEA, is provided free of charge by public school systems. Health services are sometimes covered by Special Education if they are needed to assist a child to attend school (for example, if an aide is needed to assist a child with nursing care during the school day) or if the services are determined to be “educationally relevant” (such as speech, occupational, and physical therapy). School systems are able to recover the cost of health-related services for Medicaid-eligible children.

Parent Training and Information Centers (PTIs) are also mandated by IDEA with at least one in every state. Their mandate is to provide parents with information and training about disabilities and children’s rights under IDEA and other relevant laws. They do not focus on providing information about health insurance or the health care system. Each PTI receives about \$200,000 in funds annually. Community Parent Resource Centers (CPRCs) are specialized PTIs that target underserved parents, including those with low incomes, those with limited English proficiency, those with disabilities, and those living in particular areas. Each CPRC receives about \$100,000 in annual funding.

Substance Abuse and Mental Health Services Administration, within the U.S. Department of Health and Human Services, funds several grant programs to provide mental health services to the 4.5 to 6.3 million children estimated to have serious emotional disturbances, and their families. *The Comprehensive Community Mental Health Services Program for Children and Their Families* (Children’s Services Program) provides grants and cooperative agreements to expand the mental health service system. *Statewide Family Network* Grantees provide information, referral, and support to families of children and youth with or at risk of experiencing serious emotional disturbances. *State Infrastructure Grants* strengthen the capacity of states, territories, and Native American tribal governments to develop and sustain substance abuse and mental health services.

limited knowledge of other elements of the health care and related service systems and limited time to help families find and coordinate services. Consequently, families spend a considerable amount of time acquiring basic information and learning how to navigate the fragmented health and long-term care (LTC) delivery systems.

FHICs are designed to assist families in navigating the complex system of care for CYSHCN. They accomplish this by working with families and health and social service professionals. Their primary mission is to

- provide information to providers and other professional about the multiple needs of CYSHCN,
- provide information about resources available to families and professionals,
- encourage collaboration between families and health care professionals at the personal level and in building systems, and
- provide training and guidance to families and professionals on a wide range of topics.

Having to deal with the complexity of both private and publicly funded service systems can be particularly challenging for parents who are dealing with the demands of caring for a child with extensive health care needs. Box 3 presents several real-life examples of the type of problems parents confront and how FHICs helped to address them.

Box 3. Examples of Children with Special Health Care Needs

- A 3-year-old boy has a rare, life-threatening immunologic disorder resulting in frequent hospitalizations and medication costs of \$5,000 per month. When he turned 3, he was no longer eligible for early intervention services. He was not eligible for other state services under Title V because he did not meet his state's limited criteria. To care for her son while still meeting the family's expenses, his mother quit her local job and commuted 200 miles each weekend to a higher paying position; the new schedule allowed each of the parents to care for the children at alternate times.

The FHIC provided training to help the family cope with their son's illness and prepared them to provide testimony to the state legislature about his needs. The family's testimony contributed to passage of a bill funding a study to examine the needs of children with special health care needs in their state. The family's testimony also helped educate legislators about the importance of family subsidies for respite care and travel expenses associated with obtaining medical care.

- A 6-year-old girl with developmental delays that responded to speech therapy services was denied further service by her insurance company. Her parents stopped therapy because they could not afford to pay out of pocket for the services. The FHIC provided information about appealing the decision.
- The parents of a boy with autism did not know what services were available for him and their other children were having trouble adjusting to his condition. The FHIC put his mother in touch with the Parent-to-Parent program and a workshop for siblings. It also provided information about several resources, including Medicaid and early intervention services.
- The 11-year-old son of a single, working mother requires 24-hour care. His many conditions include spina bifida resulting in paraplegia, hydrocephalus, and visual impairment. Because he can not turn himself in bed, he requires a special airflow mattress to prevent bed sores. His 8-year-old mattress has been broken for 18 months, and the various state agencies disagree about whose responsibility it is to replace it and whether he has to have severe bed sores before he is eligible for a replacement. To protect her son from painful and dangerous bed sores, his mother wakes herself every 2 hours to reposition her son in bed. The FHIC helped identify resources to help her get a new mattress approved.

Section 3 Grantee Activities

The need to educate and provide support so that individuals and families have the information they need is crucial to the health and well-being of CYSHCN. Families of CYSHCN often require a great deal of information and assistance to ensure access to quality health care and community supports. To address the lack of knowledge about insurance coverage (public and private) and community services and supports available to CYSHCN, the FHICs engage in a wide range of activities:

- providing information and referral services
- developing and disseminating informational materials
- educating families and professionals
- promoting family-centered care and medical homes
- improving disaster preparedness and response for CYSHCN
- improving programs and informing policies that affect CYSHCN
- developing partnerships

These are described in the following sections.

The FHICs' ultimate goal is to equip families with knowledge to navigate the system and to assist them to obtain services and supports for their children. However, because medical providers and other professionals are not always adequately informed about services available to CYSHCN outside the medical system, such as educational services, support groups, and respite services, FHICs also target some of their activities, most notably information and referral services and educational initiatives, to providers and other professionals.

Information and Referral

Grant staff provide extensive one-on-one information and referral services to both families and professionals. Indeed, this is one of their main functions. According to a report compiled in 2005 by Family Voices, the national technical assistance contractor, 21 FHICs responded to 222,724 requests for information in a 12-month period.¹⁰ Inquiries are made by telephone, e-mail, and in person at FHIC offices; during outreach visits to physicians' offices and specialty clinics; and at parent group meetings. About two-thirds of these requests come from families and a third from professionals.¹¹ Individual FHICs report that the call volume has been increasing as they have become better known and as some have extended their services through regional offices around their states.

Families

Families request several types of assistance: help identifying available health resources and community services; information about their children's medical conditions; information about health care financing issues, including understanding their health insurance benefits (both public and private) and insurance appeals processes; and helping with the application process for public benefits like Medicaid, Early Intervention services, the State Children's Health Insurance Program, and Supplemental Security Insurance (SSI) program. Apart from the FHICs, few entities or individuals are funded to provide these services, although care coordinators in some programs, such as Title V, are able to provide some assistance to families of eligible children.

Many of the calls handled by the FHICs deal with questions about Medicaid benefits. Both families and health care providers lack basic information about Medicaid eligibility and the services it covers. In many instances, parents are unaware of basic benefits and program provisions. The FHIC in Wisconsin provided several examples of parents' need for information about their children's Medicaid coverage. For example, a single parent was afraid to work because she thought her income would disqualify her child from Medicaid eligibility. The FHIC informed her that Medicaid has special rules for determining eligibility that exclude consideration of the parents' income for children who would otherwise require institutional care.¹²

Other parents were not working or were at risk of losing their jobs because they did not know that Medicaid covers personal care that can be provided after school hours. Some parents are lacking even the most basic information about what durable medical equipment is covered, such as wheelchairs. One family did not know that Medicaid covers bathing devices and called the FHIC to find out what assistance was available to help them lift their ventilator-dependent child in and out of the tub.

Just knowing the limits of the service system can help families and providers apply their own efforts more efficiently. In the absence of public resources specifically designed for their children's needs, FHIC staff will refer families to charitable organizations and to mainstream and inclusive services, like day camps and after school programs. They also provide information about how to approach these and other programs about including children with disabilities or chronic conditions.

The FHICs can also tap into the knowledge of their peers in other states. This is particularly useful when families are moving to another state or, for example, when a family from South Dakota is taking their child to Boston for surgery. Through a national network, the FHICs are able to help families identify local resources and understand the services available in each state.

The parents we interviewed said that they received the information they needed about support services or public programs from the FHICs, not the health care system. In addition, the FHICs provided education, training, peer support, and links to other resources. After their first contact with the FHICs, they received ongoing information through newsletters and e-mails and turned to the FHIC for assistance when they faced new issues and challenges.

Professionals

Health and social service professionals call the FHICs looking for information to pass on to the families they serve. One FHIC reported that half of the calls they receive are from professionals, including social workers, case managers, nurses, physicians, and other ancillary health providers. Due to the boundaries of their responsibilities, high case loads, and frequent staff turnover, case managers and care coordinators in the formal service system often have narrowly specialized knowledge, for example, of the services available under Title V. Even seasoned medical care providers specializing in CYSCHN don't have the time or staff to learn the myriad details of all aspects of the care system and to keep up with the constantly changing rules regarding eligibility and covered services.

Social work staff at medical centers report that they frequently refer families to their states' FHICs, particularly when children have first been diagnosed with special health care needs. They recommend that families get on the mailing list, learn about new programs or trainings, and bring their specific questions directly to the FHIC staff. Staff in pediatric practices report they also will call on FHIC staff to help them develop strategies for providing family-centered care.

"My first contact with SPAN [the New Jersey FHIC] was when I first learned of my son's diagnosis. The neurologist explained the diagnosis, but not the different places that I could reach out to for help. I found SPAN on the Internet. I needed information about everything. Where do we go from here? How do you develop a plan to help the child? Nobody tells you these things.

"SPAN first provided an ear, someone to whom you can tell your list of immediate worries. They gave me information (e.g., about insurance, Individualized Education Plans, special needs law information, seminars, and trainings). If they don't have the information you need, they tell you where you can find it and they e-mail information if there are trainings being offered by other organizations. They told me about another program, Parent to Parent, so I could talk with a parent whose child has similar problems. I also found out about sibling support groups through SPAN.

"Now I call them whenever I have questions or to get an idea of the outcome to expect. They tell you the good, the bad, and the ugly. To know what you are getting into before you get into it is really helpful." —Parent

"I know the FHIC will follow through with the referrals I give them, that the family will be well educated and well informed and get a more parent-to-parent basic understanding of the information than my 30 years of social work experience or 60 minutes with them in a clinic can provide." —Specialty clinic medical social worker

Development and Dissemination of Information Materials

Parents of children newly diagnosed with a special need are often overcome by the news and are rarely prepared to deal with the challenges they face in caring for CYSHCN. They do not know where to turn for assistance and can become overwhelmed trying to navigate through the systems that provide essential services for their children. To help them understand the maze of services and supports, families need information that is easy to understand and helps them to coordinate their children's care and advocate for the services they need.

"The more families can obtain information, the better they are able to advocate on behalf of their children." —FHIC Director

Materials Development

In addition to providing one-on-one information and referral services to families and providers, FHICs are developing informational materials. By doing their own research to identify existing materials and conducting surveys and focus groups with families, FHIC staff, themselves often parents of children with special needs, found that much of the information families need did not exist in written form. Materials that were available generally were not targeted to families of CYSHCN, were not culturally competent or linguistically appropriate. While some materials were available in languages such as Spanish, or Hmong, most were available only in English.

To fill these gaps, Grantees have developed a range of materials, including newsletters, brochures, information packets, and fact sheets. Many of these materials were developed by combining information from existing sources or modifying or adapting materials to be state specific. If no information sources were available from which to draw, Grantees developed materials based on their own knowledge, experience, and research.

Several of the FHICs regularly publish newsletters targeted specifically to families' needs. These newsletters deliver information to families about a wide variety of topics, ranging from home and community services and changes in Medicaid to information about upcoming workshops and training opportunities. The newsletters also contain links to Web sites, phone numbers, and other resources that families can consult for services and supports.

Because managing care for CYSHCN can be a challenge, Grantees have also developed technical materials to assist families in managing their children's care. Several have developed "resource notebooks," which compile lists of health and related services together with other resource materials into a single document that families can use to locate services and supports for their children. Resource notebooks typically contain information on specific topics, such as Medicaid eligibility, the State Child Health Insurance Program, Medicaid's Early Periodic Screening, Diagnostic, and Treatment (EPSDT) program, and services available under each of these programs, such as personal care, respite and other in-home

and community services. These notebooks also list information about other services and supports available to families of CYSHCN, such as summer camps for children with disabilities.

Some Grantees have developed “care notebooks,” recordkeeping systems to help families work with providers and keep records of their children’s care. These notebooks are generally tabbed three-ring binders that provide an organized place to keep information about their child’s medical history, lab reports, evaluations, treatments, daily activities, appointments, and medical expenses. The FHIC resource center staff in one region of Vermont coordinates with the local pediatric practices to host twice-yearly care notebook “fiesta nights.” At these events, pediatricians make children’s files available so that families can photocopy items to update their children’s care notebooks.

Parents use the information in these notebooks to help them advocate for their children’s care at medical appointments and during individualized education program (IEP) meetings.¹³ They can also use them at home as a daily care plan for themselves or paid caregivers (e.g., providing appointment reminders and information on medication administration). The North Dakota FHIC is developing a care notebook specifically designed for youth transitioning to adulthood.

“The workbook that they created and put together for us is incredible. It makes keeping track of my son’s care a lot easier.” —Parent

Other Grantees have developed materials to help them more efficiently deliver services to families. For example, California developed templates for Family Resource Network staff, who provide parent-to-parent support for families with children age birth to 3, to help guide them in providing information and referral services to families and to help them with information dissemination to hospital-based providers. North Dakota developed a referral form to assist providers in identifying families who might benefit from the services of the FHIC.

Ethnic and multicultural families often have an additional hurdle to overcome in caring for their CYSHCN because they do not have access to information in their native language or to culturally sensitive materials. To meet the information needs of diverse populations and assist families who are unable to speak or read English, many FHICs translate their materials into languages common in their states, such as Spanish, Portuguese, and Chinese.

“Parents are able to get information in Spanish. This is really important for us. They have provided pamphlets in English and Spanish, and their Web site has some Spanish information also. It is very important for us as a community.” —Community Partner

In addition to informational materials on home and community services and supports available to families, many FHICs also develop comprehensive brochures for outreach

purposes. These brochures contain information about the FHIC, including the services it offers, the Web site address, and a toll-free number. These outreach materials are also translated into other languages.

Materials Dissemination

Grant funding has enabled Grantees to disseminate their informational and educational materials in various formats and venues, such as CD-ROMs, DVDs, and Web sites. The majority of Grantees use Web sites to provide information and education materials, including brochures, newsletters, and fact sheets. Several FHICs' Web sites also include links to information, documents, and materials on other organizations' and agencies' Web sites, facilitating access to information on a wide range of both general and specialized topics from various sources.

Families are using these Web sites to obtain information, as evidenced by the number of hits these sites receive. *Support for Families with Disabilities* (the California FHIC) reported over 400,000 hits to its Web site during the second quarter of last year. During the last fiscal year, over 1,000 requests were made to *Family Voices of North Dakota's* (the North Dakota FHIC) Web site, which provides access to 25 publications and 31 different resources targeted to families.

Newsletters are most commonly distributed through electronic mailing lists. During 2004, *Parents Let's Unite for Kids*, the Montana FHIC, had 1,884 subscribers to its e-newsletter. Electronic mailing lists are also used to provide information and support to families. Because many individuals, especially those in rural or low-income areas, do not have computers and are not able to travel to local libraries to use one, FHICs also use grant funding to disseminate print copies of their materials. Newsletters are distributed through regular mail to those who request print copies.

The FHICs provide technical materials like the care notebooks directly to families who contact them for assistance. These materials are made available in different formats, such as hard copy and CD-ROM, to meet families' needs and preferences. Several FHICs also make materials available for download from their Web sites. A few FHICs found that while some families do not have computers, they often have DVD players and so they began providing their training and other informational materials in DVD format.

Partner organizations like the state chapter of the American Academy of Pediatrics, the Title V programs, and individual pediatricians and case managers also assist FHICs with dissemination. Several of these organizations print the care notebooks and provide them to the families they serve. Some also post the care notebooks on their own Web sites. Educational institutions and state agencies in some states also help disseminate materials.

For instance, in North Dakota, the Department of Public Instruction helps the FHIC provide the youth care notebooks to youth who are transitioning to adulthood.

Many FHICs rely on existing or newly created networks to help with outreach efforts. They distribute brochures about their services along with other informational materials at conferences, at physician offices, and at social service and other agency offices. For instance, the Kentucky FHIC staff attended and staffed a booth at a conference about exceptional children where 2,000 parents, providers, professionals, teachers, and representatives from several state agencies were also in attendance. FHIC staff and parent mentors informed families and providers about the FHIC and distributed informational materials about services and supports available to families. Some FHICs also provide outreach materials and information to state agencies and attend provider meetings and family support groups to disseminate information about their services.

Education Initiatives

The FHICs' educational initiatives are designed to provide comprehensive information on specific topics for parents and professionals. This provides both groups with an efficient way to learn about systems of care, approaches to managing the needs of children and families, and new developments, as well as the opportunity to network.

Educating Families

In addition to providing individualized assistance to families, FHICs educate many different groups using a variety of methods. One of the most common approaches used is the train-the-trainer method. Once parents are trained, they return to their respective communities and teach others what they have learned. Some also use what they learn in their roles as parent mentors. In this way, FHICs are able to educate more parents statewide. See Box 4 for information about a training program conducted by the Wisconsin FHIC.

Grantees cover a wide range of topics in their trainings and workshops, with a major focus on health care financing options including Medicaid and private insurance. Specifically, they address the following:

- understanding what is covered by insurance
- obtaining services
- working within the insurance system
- understanding the appeals process
- understanding Medicaid
- obtaining prescription drugs through Medicaid/Medicare

Box 4. Family Voices of Wisconsin's Train-the-Trainer Program

Family Voices of Wisconsin, the Wisconsin FHIC, has developed a curriculum and materials for its train-the-trainer program. The training program covers a range of topics, including Medicaid eligibility services. *Family Voices* recruited 35 parents from across the state and gave them a \$75 stipend to attend a 1-day training session at a central location where they learned how to use the curriculum to train other parents in their respective communities. The FHIC supports these parents by giving them additional training and materials to distribute. The FHIC also holds monthly conference calls with the trainer parents, who are paid a \$250 stipend for each session they conduct. These conference calls provide an opportunity for parent trainers to ask questions, share experiences, and receive additional training. The FHIC has been successful in negotiating a contract with the state's Title V program to continue the training program after the grant ends.

Grantees provide workshops and trainings on many other topics as well, including the following:

- Medicaid home- and community-based waiver programs
- self-directed services and self-determination
- supports available to assist children with community living
- Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Services—one of the services states must provide for Medicaid-eligible children under age 21
- Medical Home

Trainings and workshops for parents are designed to support them in their role as advocates for their children. FHICs also provide workshops to meet the specific needs of parents, such as how to cope with stress. In these workshops, parents learn how to recognize and acknowledge stress and to identify strategies for coping.

"My husband attended a workshop and learned that the most important role he can play is to support me. Now he recognizes that it is important for me to take breaks from caregiving, for example, going for a walk. The workshop has enabled both of us to deal with the struggles we face caring for our son together as a team." —Parent

A few Grantees have education initiatives that focus on transitioning children to adult systems of care. For example, *Parent to Parent of Vermont* partnered with the Parent Training and Information Center (PTI) to conduct a series of statewide transition trainings, bringing together information about health care financing with information about transition to adult services. These sessions provide an

overview of transition options and empower youth to advocate for themselves and for their parents to advocate for them as well.

Other topics covered by FHICs' education initiatives include building collaborative relationships, communicating with providers, leadership and legislative advocacy, and care coordination. Family members find these sessions both interesting and useful in their efforts to advocate for their children. One family member told us she used the training to help her prepare and share her family story with the state legislature, which she felt had a positive impact on educating them about issues faced by CYSHCN.

FHICs provide trainings using a variety of methods. Many are conducted in-person, but some FHICs use teleconferences. These FHICs hold teleconferences with guest speakers, often at lunchtime to make them accessible to working parents. Prior to the teleconference, participants obtain materials from the FHIC's Web site or request hard copies or CDs of materials. They then follow along with the presentation while listening by phone. Some FHICs also offer videoconferencing and subsequently make the video tapes available for viewing on Web sites. Other FHICs make DVDs or video tapes available so parents can view the training at a time that is most convenient for them. Several FHICs are also exploring Web-based training options.

To increase access to training for non-English speaking families, many FHICs partner with cultural organizations. Such collaborations go a long way in establishing trust within minority communities and can significantly increase participants' knowledge and understanding.

Educating Professionals

Health care and other professionals who assist families of CYSHCN face challenges when seeking to provide accurate information about services and benefits. Medicaid and state program rules, regulations, and eligibility requirements may change from year to year. Providers have to deal with multiple private insurers in addition to public programs, and plans may differ with regard to benefit coverage, authorization procedures, and reimbursement policies. To help them stay current, providers need a reliable source of information and educational opportunities.

Even though care coordinators and case managers—such as those in the Early Intervention and Title V systems—can be very knowledgeable about their own programs, many lack knowledge of the other systems of care available to CYSHCN. High case loads are common and case managers have limited time to obtain information about other programs' services or to find information for families. Pediatricians and social workers may want to provide family-centered care and provide medical homes for CYSHCN (discussed below), but many lack the training to do so.

FHICs play an important role in meeting these professionals' education needs. While FHICs primarily target their education initiatives to parents and families, they also educate professionals and health care providers. School personnel, social workers, and state officials are often invited to participate in education opportunities. As one Grantee reported, FHICs provide trainings and invite state leaders so they can hear about the problems families face on a day-to-day basis and the lack of funding and resources available to address those problems.

FHICs educate health professionals by offering them trainings and workshops (as described in an earlier section of this report), by developing opportunities for family members to educate professionals directly, and by working with committees focused on improving medical care to children with special health care needs. Parents serve on educational panels and health care committees, speak to college classes, and meet individually with medical students; pediatric residents; and nursing, social work, and other health professionals in training.

*"At a workshop for our county social workers, we had a family member tell them what it was like to go into the county social service office and it was a real eye opener for them."
—FHIC Director*

The grant program has helped some FHICs initiate training and workshop activities for the first time, and helped others to expand their efforts in this area. For example, in 2005, *Parent to Parent of Vermont's* Family Faculty Program had about 100 family member participants, a major expansion over previous years.¹⁴ FHIC staff recruited parent participants from a network of families who sought help or volunteered in other ways for the Vermont FHIC. Grant funds have also partially supported both the Utah and Vermont FHICs participation in classroom and other training opportunities with pediatric medical residents. Families teach residents about the positive impacts and challenges of having a CSHCN, how to meet the needs of families of CYSHCN, and what it means to provide family-centered and culturally competent care.

*"In the Family Faculty program, medical students meet a family who tells them about challenges they experienced with the medical profession and what would have helped or not helped. These stories stay with physicians and influence their practice."
—Professor of Medicine*

Promoting Family-Centered Care and Medical Homes

Education to promote the adoption of the medical home concept and family-centered care is a major component of FHICs' educational activities. Promoting family-centered care and the medical home concept are core expectations of the HRSA FHIC grants and are activities of the CMS Grantees as well. See Box 5 for a description of these two service approaches.

Box 5. Definition of Family-Centered Care and Medical Home

Family-Centered Care. The Maternal Child Health Bureau Division of Children with Special Health Care Needs defines family-centered care as assuring the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship. Family-centered care is the standard of practice that results in high-quality services. It emphasizes family-professional partnerships, information sharing and communicating effectively with families, including families in decision making, and respecting their preferences.¹⁵

Medical Home. The American Academy of Pediatrics defines a medical home as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. In a medical home, a pediatric clinician works in partnership with the family and/or patient to assure that all of the medical and non-medical needs of the patient are met. Through this partnership, the pediatric clinician can help the family and patient obtain and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child or youth and family.¹⁶

According to the Survey of Children with Special Health Care Needs, while most children with special health care needs have a usual source of care, about a third of families do not have access to services consistent with the definition of a medical home. FHICs are working to promote medical homes and family-centered care in several ways, including collaboration with their state's Title V program and other groups such as the state chapter of the American Academy of Pediatrics.

They also participate on state committees devoted to improving family-centered care and increasing the availability of medical homes, and work directly with individual medical practices to develop a collaborative practice style. Physicians working with the FHICs to implement family-centered care report they spend more time making sure they know what issues are important to families, what questions they have, discussing families' cultural and traditional practices, and speaking directly to specialists when making referrals.

"A clear benefit of this approach is that families understand the purpose of the doctor's recommendations and follow through with them because they are part of the decision-making process and don't feel left out. I also call the FHIC staff when we are struggling with a family with multiple challenges and I am not sure how to proceed in a family-centered way and need additional information about available resources."

—Director of Social Work

The FHICs support the coordination role of a medical home by serving as a resource for physicians and their office staff regarding service and health coverage issues. Medical practice staff also call FHICs for advice about engaging effectively with individual families. In addition to fielding individual calls for information, the FHICs provide “one-pagers” on a variety of topics, such as EPDST. Educational materials are designed for physicians and for the families who visit them. Some information is sent directly to physicians; other materials are prepared for distribution to families during physician visits. In addition, projects like the care notebooks described previously encourage collaboration between families and medical providers.

“Working on medical home implementation includes helping a doctor to provide the information families need to make choices about next steps and to non-judgmentally support a family to make decisions. There are multiple treatment choices and a family needs to be supported to make the choice that’s right for them without feeling imposed upon to make a different decision.” —FHIC Director

Disaster Preparedness

Hurricanes Katrina and Rita brought disaster preparedness into the national spotlight, especially for vulnerable populations including people with disabilities and those who are medically fragile. Organizations like the FHICs have a valuable role to play in improving disaster preparedness, response, and recovery efforts because they have detailed knowledge of the needs and resources available to children with special health care needs. Although this is not a core activity funded by the grant program, the FHICs are involved in this issue to varying degrees. Their activities include the following:

- conducting outreach to identify and assist families evacuated from disaster-stricken areas to their states to help them find appropriate housing and information about the service system in their states and to connect them to other families for support
- disseminating information materials for families about disaster preparedness on their Web sites, through their electronic mailing lists, and as handouts
- providing sample emergency information forms summarizing medical information and contact information, which families are advised to keep with their children at all times
- working with local emergency medical services on protocol development to ensure appropriate services are available and provided to CYSHCN
- participating in local, state, and national committees to ensure that the evacuation and relief needs of CYSHCN are addressed in disaster planning¹⁷

Improving Programs and Informing Policies

Programs providing services to CYHSCN may not always recognize or address their or their families’ unique needs and perspectives. Policymakers and program administrators may not

understand how specific policies and program provisions affect service delivery, and coordination between programs in the various systems may need improvement.

Consequently, educating policymakers and other stakeholders about the needs of CYSHCN and the challenges their families face is critical to assuring the quality and timely receipt of services. Family input can help programs improve effectiveness and efficiency, for example, by decreasing unnecessary complexity.

Private insurance companies also need educating about the unique needs of CYSHCN. For example, policies regarding coverage of physical and occupational therapy are generally based on an acute rehabilitation model where therapies are provided for a limited time to restore function after an illness or accident. In contrast, CYSHCN often have ongoing or intermittent needs for rehabilitation therapies at various stages of development. Similarly, policies regarding coverage of durable medical equipment need to recognize that wheelchairs will need to be refitted or replaced as children grow.

Working to improve the quality of care through medical home and family-centered care initiatives is one example of FHICs' work to improve the system. They also engage in activities designed to address other system problems that families face, in addition to those cited above. Their mission includes communicating with state policy makers about program and policy issues that affect CYSHCN and providing parents with the opportunity and training needed to play a role in the policy-making process. Federal sponsorship of the FHICs helps them to play a meaningful role in these processes by increasing their visibility and perceived legitimacy.

Examples of FHICs' work in this area include the following:

- serving on state and local advisory boards and committees
- encouraging parent participation in agency, board, and committee meetings to provide a consumer perspective
- identifying parents in response to requests from organizations and state and local agencies to serve on boards and committees
- communicating and collaborating with state agencies and other organizations
- tracking legislation and policy that affects CYSHCN
- training parents about the policy-making process and providing updates to parents and providers about current issues relevant to CYSHCN
- educating, training, and supporting parents to effectively communicate with policy makers

Examples of other areas the FHICs are working on include the following:

- educating policy makers about the benefits of a range of home and community services that improve children’s health and functioning, allow some parents to work, and reduce the risk of costly institutional placement that separates children from their families
- working with the state agency to revise the Medicaid claims process for therapy services to more accurately determine the needs of CYSHCN by having a pediatric task force review claims
- educating legislators about the value of state family support payments that help families cover costs related to their children’s health care that are not reimbursable

Developing Partnerships

Collaboration and effective partnerships are critical to the FHICs’ ability to achieve their goals and to avoid duplication of efforts with other organizations providing assistance to families. Many of the FHICs also believe partnerships are essential in their ability to sustain their work. Indeed, as evidenced throughout this paper, these partnerships are important to FHICs’ efforts to disseminate materials, to conduct outreach to families and professionals, and to participate in policy-making activities.

Most FHICs are partnering with the Title V programs in their respective states to provide information and referral services to families, or to ensure the family perspective is represented in policy decisions. For example, California worked with the Title V agency and other groups around the state to create a statewide panel to work on issues related to family-centered care. *Statewide Parent Advocacy Network of New Jersey, Inc. (SPAN)*, the New Jersey FHIC, participated with the Title V program in a statewide needs assessment related to transition to adult life for youth with special health care needs as part of the Maternal and Child Health Bureau block grant application.

The FHICs also collaborate with other entities:

- state and local agencies and programs
- hospitals and medical practices
- tribal organizations
- universities
- public school districts
- managed care organizations
- other nonprofit organizations

These collaborations take many forms and enable FHICs to address a range of issues. The Indiana Parent Information Network, Inc., Indiana's FHIC, receives funding from two managed care organizations to provide information and referral services to families of CYSHCN. One managed care organization pays an annual fee per family, the other pays the FHIC a monthly fee based on the projected number of inquiries. Collaborations fostered through the FHICs' participation on task forces and special committees provide the FHICs with opportunities to influence policies that affect CYSHCN. For example, the New Jersey FHIC informed legislation to increase health insurance coverage for children under the State Child Health Insurance Program. The FHIC was also able to secure an agreement from the Department of Health to develop and submit a request to CMS for a Medicaid waiver program for Early Intervention services.

As a member of the Real Choice Systems Change Grant family, some FHICs were invited to participate on Real Choice Systems Change Advisory Committees. In this capacity, many of the Grantees have been instrumental in bringing attention to the issues affecting CYSHCN. For example, the North Dakota FHIC is partnering with other Systems Change Grantees to look at issues affecting youth age 14 to 21, with a particular focus on youth transitioning to adulthood.¹⁸

Section 4 Challenges

The FHICs face a daunting task given the modest funding that they receive, the high demand for their services, and the limitations of the health and social service system supporting CYHSCN and their families. Throughout this paper, we have highlighted the work these organizations do to reach as many families and providers as possible through the use of the Internet, trainings and workshops, developing volunteer capability, and working on systems change within their states. However, CMS funded organizations receive only \$50,000 per year, and HRSA Grantees receive \$96,000 per year on average.¹⁹ With this limited funding, Grantees face substantial challenges to developing a fully functioning FHIC that will reach all those who need their services statewide and will be able to bring about systems change.

In this section, we present information about some of these challenges and the activities FHICs are taking to address them.

Inadequate Staffing

Supporting an adequate number of staff to maximize the FHICs' impact is the central challenge for these organizations. Essentially, these programs must draw on the commitment of their staff, many of whom have personal experience as parents of CYHSCN, and on volunteers. As calls to the FHICs increase over time, staffing will be inadequate without additional funding. The FHICs reported using a variety of flexible staffing approaches to maximize available funds:

- Employing staff on a part-time basis. This allows family members with caregiving responsibilities to participate as staff members. Part-time staff frequently do not receive health insurance and other benefits, which keeps costs down but sometimes leads to staff turnover.
- Using funding to increase current staff's knowledge and expertise. For example, in organizations that are also PTIs, some FHICs are using grant funds to enable existing staff to become experts in health information or spend time developing educational materials.
- Cross training FHIC and PTI staff. This approach allows each organization to help families navigate both the special education and health care/health insurance systems.
- Sharing staff with other organizations.
- Recruiting additional family members as volunteers.
- Using student interns, VISTA and Americorps volunteers.

Inadequate Resources to Serve Diverse Groups

Given limited funding, it is not possible for FHICs to extend their reach to all families who need their services. While the Internet is an efficient and low-budget approach to information dissemination, it does not reach families without computers or Internet access. In addition, translating materials into the most common languages, such as Spanish and Chinese, or hiring one or two bilingual staff members is insufficient to meet the needs of the many different linguistic groups, and even these measures are only feasible for some of the larger, more established organizations. Thus, many challenges remain to providing consultation or information and referral services to many of the families who need this information. FHICs are trying different approaches to address these challenges:

- using teleconferencing, e-learning modules, and DVDs for training
- subcontracting with members of specific communities to coordinate trainings or to translate materials, for example working with tribes, inner city organizations, and religious groups
- conducting outreach through local health care providers, including primary care practices and hospital specialty clinics
- partnering with nonprofit groups that represent the interests and needs of ethnic and cultural minorities

While the FHICs are reaching many families and developing creative solutions to reach specific groups, the Grantees identify several groups for whom additional funding is needed:

- families with limited ability to speak or read English, the number and diversity of which are growing in some states and localities
- rural and frontier families whose geographic isolation makes them difficult to reach and limits their opportunity to meet with other families or professionals who might assist them to identify their children's needs or link them to health care or other services
- military families who need information about their health insurance coverage and may need assistance finding resources when they relocate
- Native American families living on reservations, who face the same challenges as other rural families and whose challenges are compounded by the limited resources available through Indian Health Service and limited access to transportation, telephone, and Internet services
- low-income parents working several jobs, who have limited opportunities to learn about resources or participate in workshops and trainings
- other minority and disadvantaged groups, including families with substance abuse problems, those with low educational levels, and those with limited literacy

Obstacles to Parent Participation

Despite FHICs' commitment to maximizing parent participation, financial and time constraints limit some parents' ability to engage in the full range of activities offered. Parents are limited in their ability to participate in trainings, to volunteer with the FHICs, or to sit on advisory boards and committees by a number of factors: their caregiving responsibilities, the expense of arranging care for their children while they attend, and in large states or rural areas, long travel times and high travel expenses.

FHICs have had partial success in supporting parent participation by using grant funds to cover respite services for parents, to provide small stipends for travel expenses, and to provide on-site respite services during events. Some FHICs generate revenue to support parent participation by charging professionals and agency staff who attend their training sessions and workshops. Others have succeeded in obtaining funds to support parent participation from collaborating organizations and agencies, including the Title V program and the state Department of Public Health. Nonetheless, the need for respite services and the expense of attending meetings and workshops continue to be major ongoing challenges to parent participation, particularly for parents with preschool children.

Data Collection

Data collection can generate valuable information for the FHICs' own planning and evaluation purposes and to help them communicate the needs of CYHSCN to state legislatures and state agencies. Yet for many Grantees, data collection is a major challenge. Only the HRSA Grantees and some CMS Grantees receive funding for data collection. FHICs housed within *Family Voices* chapters (the majority of FHICs) are also expected to try to collect data and submit it to the national headquarters, regardless of funding source requirements, although this occurs to varying degrees.

The key data collection elements regarding FHIC information and referral services are the number of contacts, who the contacts are (family members vs. professionals; first time callers vs. repeat callers), and the issues and problems people are calling about. As the FHIC Technical Assistance provider, the national *Family Voices* organization works with Grantees on data collection at their request. To the extent FHICs' ability to collect data is dependant on current grant funding, this activity is unlikely to continue after the grant funding ends.

In addition to a lack of ongoing financial support, FHICs face other challenges:

- determining and establishing agreement about what data to collect
- providing training to local organizations to support data collection activities
- obtaining uniform data from multiple sites often staffed by volunteer parents

- coordinating with reporting requirements made by multiple funders
- coordinating the training and reporting for outstationed staff or satellite operations

Additional Challenges

FHIC staff reported additional challenges, including those related to establishing a new organization or providing new services, those related to competition for funding, and those related to efforts to sustain their work.

Growing Pains

The FHICs' success is a double-edged sword, creating increased demand for information and referral services, trainings, and participation on state and community boards, all of which strain limited resources. In addition, questions raised by family members often extend beyond health care and health insurance issues. FHICs have to become increasingly knowledgeable about other aspects of the service system—for both children and their parents—and to learn how to respond when families bring up difficult issues like domestic violence. While many FHICs are experiencing rapid growth in the demand for their services, some of the small, newer FHICs find it is taking longer than anticipated to become established, particularly in rural areas where families have limited Internet access.

Professional Bias and Competition for Funding

The FHIC philosophy focuses on bringing the experience and expertise of parents of CYSHCN into the policy-making arena, yet bias favoring professionals' opinions still exists in many areas. Some FHICs are finding it difficult to overcome this bias and others find themselves competing with professional groups for funding. Decreasing state agency budgets can also lead to turf battles over this work as other organizations investigate whether they can get funding for the services FHICs are providing. FHICs have addressed these issues by working with various key agencies in advance to carve out a role that avoids duplication and turf battles.

Finally, as discussed in the section on policy-related activities, the "systems" that FHICs teach parents to navigate remain complex and in need of reorganization. For example, Grantees report that some home and community service programs seem to be developed without any awareness of other programs. Additionally, because some programs require specific diagnoses for eligibility, serving children with multiple diagnoses can prove difficult.

Sustainability

As discussed earlier, the grants are intended as seed money, supporting organizations' efforts to establish an FHIC in each state. Because these grants are not intended to provide ongoing support to continue the work of the FHICs, Grantees need to develop plans to sustain their work when the grant ends and are pursuing several strategies to do so.

One of the most common methods is applying for additional grants. Many of the Grantees are applying or plan to apply for additional grants to sustain their work. Most FHICs are applying, alone or with community partners, for grants from state and federal government agencies and from private foundations. Others are partnering with the Title V program to write grants where the FHIC's role will involve the provision of services to parents. One FHIC reported they will be able to sustain parent trainings through a contract with their state's Title V program. The enactment of the Family Opportunity Act is bringing additional funding for which existing FHICs can compete to expand and continue their work, as well as organizations in states without a prior grant.

Other Grantees are exploring innovative and more permanent ways to support their activities. For instance, the *Stone Soup Group*, the Alaska FHIC, is investigating how it can become a Medicaid provider able to bill for family support services. They are working closely with the Title V director in the state to research this option and are using a program in Ohio as a model. *Family TIES of Nevada*, the Nevada FHIC, is considering ways to generate revenue by billing on a fee-for-service basis for the training they conduct for providers and professionals. *SPAN*, the New Jersey FHIC, has asked the state legislature to budget a line item appropriation for the FHIC. *Family Voices of North Dakota* has had similar discussions with the North Dakota Department of Human Services. *The Indiana Parent Information Network*, the Indiana FHIC, has contracts with two managed care organizations to provide information and assistance services to their members for a fee.

Family Voices, the TA provider, is supporting the Grantees in this process in several ways. Grantees commented that the sustainability tool kits and conference calls on the subject have been particularly helpful. Nonetheless, the question remains whether the FHICs will be able to continue without ongoing funding. Many of the stakeholders we interviewed stressed the importance of the work these FHICs do, but acknowledged the lack of resources to continue their work.

"If the FHIC were not operating, there would be a gaping hole—the services they provide would not be replicated or replaced in the community, nor in the state. This state has no money to replace the work they do and families' needs will not be met if their work ends." —Governor's Office Staff

Section 5 Conclusions

The FHICs are performing a vital service for CYSHCN, their families, and the professionals who provide their health and long-term care services. As evidenced by the Survey of Children with Special Health Care Needs and the experiences communicated by families, community partners, and other stakeholders, a clear need exists for the FHICs' services. In increasing numbers, families trying to make sense of a maze of programs, both public and private, are turning to FHICs for information and guidance. Between July 2004 and June 2005, 21 centers received over 220,000 calls for assistance, about 150,000 from families and 70,000 from professionals.²⁰ The FHICs also serve as an important resource to providers who consult with FHIC staff, refer families to them for additional information, and use materials developed by the FHICs to educate themselves and families. While Area Agencies on Aging have provided information and assistance for older adults for decades, no equivalent service for families with CYSHCN were available prior to the FHICs.

The accomplishments of these Grantees are impressive, particularly in light of their modest funding. They have creatively extended grant funding by forming strategic partnerships, using technology, recruiting volunteers, and to some extent developing community and regional networks throughout their states. Although funding levels limit their reach, the FHICs are clearly committed to meeting the needs of diverse populations throughout the state, including minority groups and residents of rural and frontier areas. To this end, they are exploring and testing many approaches to outreach and information sharing, arranging for translation of print and Web site materials, and partnering with community groups who can assist with entrée to their constituents and provide guidance regarding their constituents' needs.

Through their work to promote family-centered, culturally competent, and linguistically appropriate care and medical homes for CYSHCN, the FHICs are contributing to improving the quality of health care. Their innovation is evident as they devise ways to provide educational experiences for health professionals and students, as well as serving on health education advisory committees, working with coalitions dedicated to promoting medical home implementation, and working with individual medical practices.

The FHICs are also playing an important role in reshaping local and state policies and practices regarding care for CYSHCN. For example, some Grantees and stakeholders cited the need to revise outdated eligibility criteria for Title V services, which are based on former "Crippled Children" programs. With medical advances in neonatal care, many children are surviving with severe impairments and complex medical needs yet they are not all eligible for services because they do not have a specific diagnosis.

By helping families to provide a consumer perspective on program and policy issues, FHICs are helping states to develop more effective ways to assist families with CYSHCN. Their commitment and creativity is evident in the range of activities they are undertaking: trainings conducted for agency staff, matching parents with requests for consumer representation on boards and committees, and assisting parents in understanding the legislative process and providing training and support to clearly and effectively communicate their needs to policymakers.

CMS and HRSA have developed an effective grant program supported by the provision of technical assistance and opportunities for FHICs to share information and make connections across their national network, activities the Grantees value highly.

Ultimately, the FHICs' goal is to improve health and functional outcomes for families with CYSHCN. To the extent families understand what is available for their children and use services effectively, outcomes for their children will improve. These benefits go well beyond the children and families. Children whose outpatient needs are met and whose parents are able to meet their daily care needs are less likely to require hospital or emergency room care. Children who obtain home and community long-term care services are less likely to need costly institutional care.

Congress has recognized the value of FHICs by authorizing funds to establish one in every state. However the grants are time limited and not intended to provide ongoing support. These highly effective organizations require a stable source of funding to sustain outreach and referral services, information development and dissemination, and education and training initiatives.

Appendix A
Family-to-Family Health Care
Information and Education Centers

Table A-1. Family-to-Family Health Care Information and Education Centers

State	Organization	Organization Web Site	Year and Source of Award^a	Award Amount^b
Alaska	Stone Soup Group	www.stonesoupgroup.org/f2f	CMS 2003	\$150,000
Arizona	Raising Special Kids	www.raisingpecialkids.org	CMS 2004	\$150,000
California	Support for Families of Children with Disabilities	www.supportforfamilies.org	HRSA 2002	\$387,080
Colorado	Cerebral Palsy of Colorado	www.familyvoicesco.org	CMS 2003	\$150,000
Connecticut	Favor, Inc.	www.favor-ct.org	CMS 2005	\$165,000
Florida	Florida Institute for Family Involvement	www.fifionline.org	HRSA 2002	\$386,032
Idaho	Idaho Parent Unlimited, Inc.	www.ipulidaho.org	CMS 2005	\$165,000
Indiana	The Indiana Parent Information Network, Inc.	www.ipin.org	CMS 2003	\$150,000
Iowa	Family Voices at Access for Special Kids (ASK) Resource Center, Inc.	www.askresource.org	HRSA 2003	\$99,350
Kentucky	The Arc of Kentucky, Inc.	www.arcofky.org	CMS 2004	\$150,000
Louisiana	Family Voices of Louisiana, Inc.	www.familyvoices.org/F2F.htm	CMS 2004	\$150,000
Maine	Maine Parent Federation, Inc.	www.mpf.org	HRSA 2002	\$387,156
Maryland	The Parents' Place of Maryland, Inc.	www.ppmmd.org	CMS 2003	\$150,000
Massachusetts	Federation for Children with Special Needs	www.massfamilyvoices.org	CMS 2004	\$150,000
Michigan	SE Michigan Health Assoc. Parent Participation Program	Not available	CMS 2005	\$165,000
Minnesota	PACER Center	www.pacer.org	HRSA 2002	\$387,142
Montana	Parents, Let's Unite for Kids	www.pluk.org	CMS 2003	\$150,000
New Hampshire	NH Coalition for Citizens with Disabilities	www.nhfv.org	CMS 2005	\$165,000
Nevada	Family TIES of Nevada, Inc.	www.familytiesnv.org	CMS 2003	\$150,000
New Jersey	Statewide Parent Advocacy Network of NJ, Inc.	www.spannj.org	CMS 2003	\$150,000
New Mexico	Parents Reaching Out for Help, Inc.	www.parentsreachingout.org	CMS 2004	\$150,000

continued

^a Grants were awarded for a period of 3 years, with two exceptions. All but one HRSA Grantee received 4-year awards. Iowa received a 1-year set aside award.

^b CMS grants awarded in 2005 received an additional \$15,000 to purchase technical assistance in lieu of the technical assistance provided through other CMS contracts in previous years.

**Table A-1. Family-to-Family Health Care Information and Education Centers—
Continued**

State	Organization	Organization Web Site	Year and Source of Award^a	Award Amount
New York	Parent to Parent of New York, Inc.	www.parenttoparentnys.org	CMS 2004	\$150,000
North Carolina	Exceptional Children's Assistance Center	www.ecac-parentcenter.org	CMS 2004	\$150,000
North Dakota	Family Voices of North Dakota, Inc.	www.geocities.com/ndfv	CMS 2004	\$150,000
Oregon	Family Action Coalition Team	Not available	CMS 2005	\$165,000
Rhode Island	RI Parent Information Network	www.ripin.org	CMS 2005	\$165,000
South Carolina	Family Connection of South Carolina, Inc.	www.familyconnections.org	CMS 2005	\$165,000
South Dakota	South Dakota Parent Connection	www.sdparent.org	CMS 2003	\$150,000
Tennessee	Family Voices of Tennessee	www.tndisability.org	HRSA 2002	\$421,436
Texas	Texas Parent to Parent	txp2p.org	CMS 2005	\$165,000
Utah	Utah Parent Center	www.utahfamilyvoices.org	CMS 2004	\$150,000
Virginia	Medical Home Plus, Inc.	www.medhomeplus.org	CMS 2005	\$165,000
Vermont	Parent to Parent of Vermont	www.partoparvt.org	HRSA 2002	\$386,016
Washington	Washington PAVE	www.washingtonpave.org	CMS 2005	\$165,000
West Virginia	WUPTI, Inc.	www.letsgetalifewv.org	CMS 2004	\$150,000
Wisconsin	Family Voices of Wisconsin	www.wfv.org	CMS 2003	\$150,000

^a Grants were awarded for a period of 3 years, with two exceptions. All but one HRSA Grantee received 4-year awards. Iowa received a 1-year set aside award.

^b CMS grants awarded in 2005 received an additional \$15,000 to purchase technical assistance in lieu of the technical assistance provided through other CMS contracts in previous years.

Endnotes

¹ HRSA's FY 2002 Application Guidance for Competing New Proposals CFDA#93.110S

² See CMS' Web site (<http://www.cms.hhs.gov>) and the 2003 *Invitation to Apply for Real Choice Systems Change Grants for Community Living*, CFDA No. 93.779 for additional information.

³ Support for this data collection effort is provided by Family Voices' national office under a Cooperative Agreement for Health Care Information and Education for families of CYSHCN.

⁴ The Family Opportunity Act, Sec 6064, calls for the following appropriations for SPRANS grants for Family-to-Family Health Information Centers:

- \$3,000,000 for fiscal year 2007 for not less than 25 states
- \$4,000,000 for fiscal year 2008, for not less than 40 states (15 additional)
- \$5,000,000 for fiscal year 2009 and each fiscal year thereafter, in all states (10 states and D.C.)

The legislation states that such centers will undertake the following:

- assist families of CSHCN make informed choices about health care in order to promote good treatment decisions, cost effectiveness and improved health outcomes
- provide information regarding the health care needs of and resources available for CSHCN
- identify successful health delivery models
- develop with representatives of health care providers, managed care organization, health car purchasers, and appropriate State agencies, a model for collaboration between families of CSHCN and health professionals
- provide training and guidance regarding the care of CSHCN
- conduct outreach activities to families, health professionals, schools and other appropriate entities
- be staffed by such families who have expertise in federal and state public and private health care systems, and by health providers

⁵ Family Voices provides training and technical assistance to the HRSA funded Grantees through a cooperative agreement with Maternal and Child Health Bureau and to the CMS Grantees through contracts with the Office of Research and Sponsored Programs at Rutgers University and the Independent Living Research Utilization (ILRU).

⁶ The Compendium is produced every year by RTI International for CMS. It contains information about each Real Choice Systems Change Grantee, its goals, and primary activities. Abstracts of the grants are also included. The 5th Edition of the Compendium can be found at <http://www.hcbs.org>.

⁷ The survey is funded through the Maternal and Child Health Bureau, the Health Resources and Services Administration, and the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services.

⁸ Krauss, M. W., N. Wells, S. Gulley, & B. Anderson (2001). *Navigating Systems of Care: Results From a National Survey of Families of Children With Special Health Care Needs*.

Children's Services: Social Policy, Research and Practice. 2001, Vol. 4, No. 4, Pages 165-187.

⁹ Walsh, E.G. & S. Hoover (December, 2000). "Evaluation of the Diamond State Health Plan" Draft Final Report, HCFA Contract No. 500-92-0033.

¹⁰ The HRSA-funded centers are required, and funded, to collect and submit data on individual contacts. The CMS-funded centers are not required to collect data, but some do using funding from other sources.

¹¹ Family Voices, 2005. F2F HIC Data Summary, July 2004-June 2005. Available from: http://www.familyvoices.org/Information/FundedF2F_04-05.pdf.

¹² The Katie Beckett waiver program, named for the child whose situation inspired them, is one of the original waiver programs. If a state chooses to apply for a Katie Beckett waiver, the Medicaid program can disregard the income and resources of parents of children with severe disabilities who meet the requirements for institutional care. Until her state implemented this waiver, Katie Beckett was institutionalized, at great expense to Medicaid, because her family would not have qualified for Medicaid home- and community-based services.

¹³ The Individualized Educational Program (IEP) is a basic element of the Individuals with Disabilities Education Act (IDEA), which ensures educational opportunity for students with disabilities. The IEP is an agreement between the school and the parent of a child with disabilities to guide and document specially designed educational plans of instruction for each student with a disability based on his or her unique academic, social, and behavioral needs. More information about IEPs can be found at <http://www.ed.gov/policy/speced/guid/idea/tb-iep.pdf> (accessed March 13, 2006).

¹⁴ Parent to Parent of Vermont is the Vermont FHIC.

¹⁵ Reiss, John. An introduction to state Title V programs for children with special health care needs, University of Florida, Gainesville. Available from <http://cshcnleaders.ichp.edu/PDFFiles/AnIntroductiontoTitleV.pdf>.

¹⁶ The American Academy of Pediatrics National Medical Home project for children with special health care needs. See <http://www.medicalhomeinfo.org/> for more information.

¹⁷ Additional information about the disaster-related activities conducted by the Florida FHIC is included in *Family to Family Health Information and Education Centers: Promising Practices*. This paper is being prepared for CMS by Thompson Medstat as part of a series of papers on promising practices. The paper will be available later this year.

¹⁸ More information about FHIC partnerships is included in *Family to Family Health Information and Education Centers: Promising Practices* (forthcoming).

¹⁹ In 2005, funding included \$15,000 Grantees could use to purchase technical assistance directly, increasing the total funding per CMS grant from \$150,000 to \$165,000. In previous years, CMS purchased technical assistance directly for the Grantees through other contracts.

²⁰ Family Voices, 2005. F2F HIC Data Summary, July 2004-June 2005. Available from: http://www.familyvoices.org/Information/FundedF2F_04-05.pdf.