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## **FY05 Family-to-Family Report**

### **System and Impact Research and Technical Assistance for CMS FY2005, FY2006, and FY2007 RCSC Grants**

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T.O.3**

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# List of Acronyms

ABA	Applied Behavioral Analysis
CMS	Centers for Medicare and Medicaid Services
CSCHN	Children with special health care needs
CSHCS	Children's Special Health Care Services
CYSHCN	Children and youth with special health care needs
DD/MR	Developmental disabilities/mental retardation
DD Waiver	Individual and Family Developmental Disabilities Support Waiver
EIS	Enterprise Information System
FPL	Federal Poverty Level
FSN	Family Support Network
FTF	Family-to-Family Health Care Information and Education Center
FY	Fiscal year
HBTS	Home Based Therapy Services
HCBS	Home and community-based services
HRC	Health Resource Center
HRSA	Health Resources Services Administration
ICF/MR	Intermediate care facilities for the mentally retarded
IHP	Individual Healthcare Plans
I&R/A	Information and referral assistance
I&R	Information and referral
IT	Information technology
LOC	Level of care
LTC	Long-term care
MCHB	Maternal and Child Health Bureau
MR/DD	Mental retardation/developmental disabilities
MR Waiver	Mental Retardation Waiver
NAMI	National Alliance for the Mentally Ill
P2P	Parent to Parent
PASS	Personal Assistance Service and Supports
PCP	Primary care physician
QM	Quality management
RCSC	Real Choice Systems Change
SCHIP	State Children's Health Insurance Program
SSI	Supplemental Security Income
ST	Systems transformation
TA	Technical assistance

# I. Introduction and Overview

## Background

Family-to-Family Health Care Information and Education Center grants (hereafter referred to as FTF grants) were first issued as part of the 2001 New Freedom Initiative to promote home and community-based options for individuals with disabilities and chronic conditions. The first six grants were awarded in Fiscal Year (FY) 2002 by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) to family-run community-based organizations for the purposes of offering information to families and providers to improve health decision-making for children and youth with special health care needs (CYSHCN), assisting families of CYSHCN in obtaining greater access to and use of services within communities, and providing educational and leadership opportunities to family members of CYSHCN. These first grantees were supported by four years of funding with technical assistance and training provided by Family Voices, a national grassroots family organization. Following this first round of grants, the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS) became the primary funding support for the FTF grants. CMS awarded nine such grants in FY2003 and ten more in FY2004 with continuing technical assistance from Family Voices.<sup>1</sup>

In FY2005 CMS awarded approximately \$39 million in grants under its Real Choice Systems Change (RCSC) Grants for Community Living Program. The purpose of the program is to support the design and development of systems infrastructures that result in effective and enduring improvements in community long-term support systems. The FY2005 RCSC Grants were awarded under three distinct programs:

- The Aging and Disability Resource Center (ADRC) Grant Program (administered by the Administration on Aging in partnership with CMS);
- The Family to Family (FTF) Health Care Information and Education Center Grant Program; and
- The Systems Transformation (ST) Grant Program.

Ten grantees were awarded 3-year FY2005 FTF grants in the amount of \$165,000 each. Consistent with previous rounds of FTF funding, the grants were awarded to family-run community-based organizations. As specified in the FY2005 RCSC grant solicitation, the purpose of the FY05 FTF grants was to:

- Provide education and training opportunities for families with children with special health care needs;
- Develop and disseminate needed health care and home and community-based services (HCBS) information to families and providers;
- Collaborate with existing FTF Health Care Information and Education Centers to benefit children with special health care needs; and
- Promote the philosophy of individual and family-directed supports.

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<sup>1</sup> Details about FTF grants prior to FY2005 are summarized in Green A.M., et al. "Activities and Accomplishments of the Family to Family Health Care Information and Education Center Grantees." A report to U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, April 2006, which may be accessed at <http://hcbs.org/files/91/4525/FTFPaper.pdf>

This report is a cross-site analysis of the goals and objectives, outputs and outcomes, and challenges and barriers of nine<sup>2</sup> FY05 FTF grants.<sup>3</sup> Chapter II focuses on the implementation of FTF grants, the goals and objectives that guided their work, the activities and strategies they pursued, and the technical assistance they sought to support their efforts. Chapter III summarizes the outputs reported by grantees, with a focus on trainings held, and also describes the changes that resulted from grantees' efforts in terms of access and availability of services, consumer direction and control, quality, and other additional types of changes. Chapter IV concludes the report with a discussion of contextual and implementation barriers and grantee recommendations for supporting FTF efforts at the state and federal level. We also provide our own recommendations for strengthening and supporting the FTF initiative at the federal level. The Appendix for this report provides basic information about each individual grant including grant title, grantee agency, subcontractors, activities, and impacts, outcomes, and accomplishments.

## Data sources

The sole sources of data for this report were the web-based Semi-Annual/Annual and Final Report, totaling five reports for each grantee, that FTF grantees were required to complete their during the 3-year grant period. The quality of the data contained in these Reports varied greatly across grantees. Hence, evaluation findings included in this report are limited by the content and quality of these data. The Semi-Annual/Annual Report templates were identical and composed of the following major content areas:

- Progress and Accomplishments on Objectives and Activities;
- Outcomes Realized;
- Products and Outputs;
- Challenges and Recommendations; and
- Technical Assistance.

The Final Report template included these five sections from the Semi-Annual/Annual Report in addition to two sections unique to the Final Report that were intended to capture overarching, cumulative information on:

- enduring changes;
- factors that prevented progress;
- unrealized goals;
- lessons learned;
- continuing challenges in state and federal policy; and
- recommendations for state and federal policy.

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<sup>2</sup> Oregon was awarded an FY05 FTF grant, but did not implement intended activities. For this reason, we have excluded data from this grantee in our report.

<sup>3</sup> In 2005, Abt Associates was awarded the national evaluation contract for all of the 2005 RCSC grants, with an emphasis on the Systems Transformation grants. An evaluation of the FY05 ADRC grants was included as a chapter in Abt Associates Inc.'s 2008 Annual Report to CMS. Subsequent Annual Reports focus solely on the STGs. Abt and CMS decided to treat the FTFs in this separate report because the scope and scale of these grants, in particular, does not lend itself to analysis alongside the other two grant types. Abt's reports on the STGs, including 2008 report with the ADRC chapter, may be found on The Clearinghouse for Home and Community Based Services at <http://hcbs.org>

Although the Final FTF Reports were due on 12/31/08, several grantees omitted the additional sections specific to the Final Report. Subsequently, these grantees were asked to complete the sections of the Final Report in January 2010. The findings we present in this report are based on the data provided in the Final FTF web-based report and also the interim data provided in the Semi-Annual/Annual Reports. Where appropriate, data from similar sections of the reports (for example, “challenges” in the Semi-Annual/Annual Reports and “factors that prevented progress” in the Final Report) were combined in our analysis. Throughout this report we provide tables and examples in the text of grantee efforts and activities. Although we have attempted to draw our examples from as many different grants as possible, differences in data quality and availability across grantees limits our pool of examples from which to draw and some grantees receive greater mention in this report than others.

## II. FTF Grant Implementation

### Goals and Objectives

The FY2005 RCSC Solicitation defined seven overarching goals of the Family-to-Family Health Care Information and Education Centers. In responding to the solicitation and in completing their Semi-Annual/Annual Reports, grantees were asked to identify a single goal specific to their efforts and several objectives supporting that goal. The terms “goals” and “objectives” are used somewhat interchangeably in grantee Reports. In order to meaningfully summarize the scope of the FTF initiative across all grantees, the table below reflects both types of targets (i.e., “goals” and “objectives”) regardless of how they have been labeled. The first half of the table below shows how the goals and objectives identified by individual grantees align with the seven overarching goals of the FTF Information and Education Centers as defined in the FY2005 RCSC Solicitation.

**Table 1. FTF Goals and Objectives Selected by FY05 FTF Grantees**

	CT	ID	MI	NH	RI	SC	TX	VA	WA
<b>FTF Goals Specified in FY2005 RCSC Solicitation</b>									
Provide information and education on health care to CSHCN, families, and stakeholders	X	X	X	X	X	X	X	X	X
Provide training and education on HCBS services and support for CSHCN, families, and stakeholders	X		X	X	X	X	X	X	
Collaborate with existing Family-to-Family Health Care Information and Education Centers		X		X		X	X	X	
Provide information and referral to other programs and benefits that can help children remain in the community	X						X	X	X
Provide a forum for peer group discussion and interaction							X	X	
Promote philosophy of individual and family-directed supports							X		
Help families assess their potential eligibility for public LTC programs and benefits*									
<b>Other Grantee-Identified Goals and Objectives</b>									
Develop network infrastructure or capacity	X	X				X	X		X
Promote leadership					X		X		X
Develop policy and advocacy initiatives and agendas	X	X					X		
Promote partnerships between families and providers			X		X				
Identify barriers, gaps in the healthcare system, and needs for future trainings						X			X

\*No grantees chose to work on this goal.

Source: 2008 Annual (Final) FY05 FTF Grant Reports

As illustrated by Table 1, all grantees chose to focus some of their efforts on the provision of information and education on health care and nearly all (excluding ID and WA) reported a focus on the provision of training about HCBS supports and services. This emphasis on the provision of information, education,

and training across all grantees is reflected in the types of outputs they reported, which will be examined more closely in the next section of this report. Only one grantee (TX) reported a target to promote the philosophy of individual and family-directed supports, however, it is possible that other grantees felt that this target would be met through the implementation of other goals and objectives (i.e., through the provision of information, education, and training). This may also explain why no grantee chose to work explicitly on helping families assess their potential eligibility for public long-term care programs and benefits.

Some grantees identified goals and objectives that focus on aspects of FTF that, while important to the sustainability and success of the FTF, were not specifically mentioned in the FY2005 Solicitation. These are noted in the “Other Grantee-Identified Goals and Objectives” section of Table 1 and include targets such as, to develop policy agendas and advocacy initiatives (CT, ID, and TX), develop infrastructure and capacity (CT, ID, SC, TX, and WA), develop or improve partnerships between families and providers (MI and RI), and to promote leadership (RI, TX, and WA).

## Activities

Grantees pursued a number of activities and strategies to accomplish their selected goals and objectives. At the time of 2008 Annual Report all grantees reported that their activities were either completed or on schedule to be completed. Although grantees were able to specify and define their own activities for each goal and objective, the activities they pursued can be grouped into five broader categories. Examining the activities of the FY05 FTF grantees provides a more finely-grained look at differences and similarities in focus of FTF efforts than may be apparent in analysis of their selected goals and objectives alone. Table 2, below, groups similar grantee activities into the following categories:

- Developing, maintaining, and strengthening information center operational capacity
- Data gathering and evaluating
- Implementing or enhancing health information center service delivery
- Forging and maintaining stakeholder relationships
- Educating policymakers

All grantees reported some activities related to developing, maintaining, and strengthening information center operational capacity. The most frequently reported activities in this category were the hiring of staff and training of staff and volunteers for the FTFs. All but one grantee (RI) reported at least one of these two activities.

Five grantees (ID, MI, NH, TX, and WA) implemented activities related to evaluation and data gathering. NH reported three such activities, including conducting literature reviews/environmental scans, surveying families and providers to identify training needs, and conducting evaluation activities.

All grantees reported activities related to implementing or enhancing health information center delivery services. All nine grantees reported that they developed and disseminated outreach and/or educational materials. This focus on production of outreach and educational materials is also reflected in the outputs reported by grantees, which will be discussed in the next section of the report. The next most common activities in this category reported by grantees were providing information and referral to families (reported by ID, SC, TX, and VA) and raising visibility and advertising availability of FTF services and activities (reported by MI, NH, SC, and RI).

Seven grantees (CT, ID, MI, SC, TX, VA, and WA) reported activities related to forging and maintaining stakeholder relationships. The most frequently reported such activity (reported by ID, MI, VA, and WA) was identifying and strengthening relationships with community and provider partners.

Finally, four grantees (CT, ID, RI, and SC) reported conducting activities related to educating policy makers. All four of these grantees reported formulating and mobilizing support for legislative agendas related to CYSHCN and their families.

**Table 2. Activities implemented by FY05 FTF Grantees**

Activity	CT	ID	MI	NH	RI	SC	TX	VA	WA
<b>1. Developing, maintaining, or strengthening operational capacity</b>									
Train staff and family volunteers	X		X	X		X	X		X
Hire management staff and information specialists	X	X					X	X	
Develop FTF operations and communication strategy			X	X				X	X
Enhance/expand in-state peer to peer network					X	X	X		
Develop strategic plan								X	X
Develop/update tracking database			X				X		
Identify/implement strategies for sustainability				X				X	
Establish advisory board									X
Develop intake form and toolkit	X								
Convene monthly management meetings	X								
<b>2. Data gathering and evaluating</b>									
Conduct evaluation activities			X	X			X		
Conduct environmental scan/literature review on topics of interest			X	X					
Review experiences of other FTF Health Care Information and Education Centers		X					X		
Conduct survey of providers and families to identify educational/training needs				X					X
<b>3. Implementing or enhancing health information center delivery services</b>									
Develop and disseminate outreach and/or educational materials	X	X	X	X	X	X	X	X	X
Provide information and referral to families, as needed		X				X	X	X	
Raise visibility, advertise availability of FTF services and activities			X	X	X	X			
Develop and conduct trainings for families of CYSHCN (in person or web-based)			X		X				X
Develop and conduct trainings for providers (in person or web-based)			X		X				

**Table 2. Activities implemented by FY05 FTF Grantees**

Activity	CT	ID	MI	NH	RI	SC	TX	VA	WA
Modify or translate materials to enhance cultural competence				X					X
Implement usage of electronic care plans			X						
<b>4. Forging and maintaining stakeholder relationships</b>									
Identify, establish, and strengthen relationships with community and provider partners		X	X					X	X
Connect with other health information centers						X	X		
Hold parent conference							X		
Convene (quarterly) stakeholder meetings	X								
<b>5. Educating Policymakers</b>									
Formulate/Mobilize support for legislative agenda	X	X					X		
Provide recommendations and information on barriers to federal and state agencies						X			

Source: 2008 Annual (Final) FY05 FTF Grant Reports

The Appendix of this report provides a detailed listing of the activities described by each grantee in their web-based reports.

## Utilization of Technical Assistance

Unlike previous rounds of FTF, there was no national technical assistance contractor hired for the FY05 RCSC grant recipients. Rather, grantees that wanted to purchase technical assistance could do so with up to 10% of their award budget. All FTF grantees reported receiving technical assistance at some point during the 3-year grant period, but the type of TA received varied greatly between grantees. In one case (CT), technical assistance was limited to the semi-annual group conference calls to review procedures and requirements for web reporting. Other grantees purchased individualized technical assistance on grant-specific activities, such as guidance strategic planning and sustainability efforts (ID and WA), interpreting data for technical materials (VA), and increasing family participation and leadership (VA). Five grantees (ID, MI, RI, SC, and WA) reported receiving TA from Family Voices, either through the national organization or state chapters, via group conference calls (MI and RI), on-site visits (SC and WA), or regional conferences (ID). Some grantees (ID, MI, RI, and TX) reported that TA received from other FTF projects at conferences and through informal networks, was the most helpful for their efforts. Three grantees (ID, RI and VA) expressed a desire for increased interaction with other FY05 FTF grantees for sharing information about strategies and challenges. Other TA needs identified by grantees over the course of the grant period included assistance with understanding federal reporting requirements (CT and MI), help with grant closeout and transition activities (CT, RI, and MI), and identifying funding opportunities to increase sustainability (RI and MI). The mechanisms through which TA was received were captured in the grantee web-based reports in pre-defined categories, as displayed in Table 3, below.

**Table 3. Types of Technical Assistance Received by FY05 FTF Grantees**

Technical Assistance	CT	ID	MI	NH	RI	SC	TX	VA	WA
Participated in sponsored training, conference, meeting or site visit	X	X	X	X		X	X		X
Participated in teleconference or audio conferences, conference calls, or webcast		X	X	X	X		X	X	
Individualized TA on specific grantee activities		X	X	X		X		X	
Participated in grantee workgroup conference call or meeting		X	X	X		X	X		
On-site assistance from TA staff			X			X		X	
Reports, legislation, policy alerts, and other information		X		X			X		
Referrals to grantees involved in similar activities		X						X	

Source: FY05 FTF Grant Reports (2006 Annual – 2008 Final)

### III. Outputs and Changes Produced

#### Outputs

During each Semi-Annual/Annual reporting period, grantees were asked to categorize their products or outputs into the following categories:

- outreach materials
- educational materials/trainings
- technical materials
- produced reports or analyses or issues or specific topics
- new policies

Table 4, below, captures the outputs produced by grantees during the 3-year grant period. It is important to note that we found overlap in how grantees interpreted these categories. For example, materials used for outreach may also have been used for education and vice versa. Similarly, a report on best practices may be counted among educational materials as well as a standalone report.

**Table 4. Outputs Produced by FY05 FTF Grantees over Entire Grant Period**

Type of Output	CT	ID	MI	NH	RI	SC	TX	VA	WA
Outreach materials	X	X	X*	X	X	X	X	X	X
Educational materials/trainings	X	X	X*	X*	X	X	X	X	X
Technical materials	X	X		X		X			
Reports or analyses of issues or specific topics	X	X		X				X*	
New policies				X	X	X		X	

\*Grantee reported posting output on HCBS.org

Source: FY05 FTF Grant Reports (2006 Annual – 2008 Final)

#### Outreach Materials

As noted in Table 4, all grantees produced outreach materials, which included brochures, fliers, PowerPoint presentations, booklets, websites, displays for conferences, and newsletters. Four of the grantees (MI, RI, TX, and SC) also translated materials into Spanish and one grantee (MI) translated materials into Arabic. Grantees distributed these materials at events in their respective states, including conferences, presentations, trainings, and via their list serves. One grantee (NH) printed articles in state-wide circulated newspapers and magazines. Other grantees (RI, TX, and WA) also printed and distributed newsletters.

#### Educational Materials/Trainings

Most of the grantees developed training materials, as shown in Table 4, including PowerPoint presentations, booklets, brochures, and posters. Some grantees made information available online (posted on websites and distributed through list serves) and some handed out printed materials at

workshops and trainings. Across all grantees, information was distributed at support groups and centers, conferences, and at trainings. Some of the grantees adapted materials in response to feedback from their target audiences. One grantee (CT) developed a 200-page toolkit, and when they realized that their target audience would find it too cumbersome, they created one page fact sheets about the toolkit’s contents, and put the information on thumb drives. Another grantee (NH) also created tools to evaluate emergency preparedness plans for children and physical disabilities in schools and wrote a brochure about emergency “To Go Kits.”

Generally, the FTF training activities targeted grant and information center staff, professionals, or families, or some combination of these three audiences. Many of the grantees (NH, RI, MI, TX, and VA) reported that they conducted trainings, but did not consistently specify the target audience, content, or topics of the trainings. Table 5, below, summarizes training topics for FTF grant staff and volunteers across those grantees (CT, ID, and SC) that specifically mentioned staff trainings.

<b>Training Topics</b>	<b>CT</b>	<b>ID</b>	<b>SC</b>
Health care financing	X		
Use of 1-800 phone line		X	
Cultural competence		X	
IT/Database training		X	
Grant sustainability		X	
Consumer Directed Services (e.g. Medicaid Waivers, referral form)			X
*NH <sup>4</sup> , MI, RI, TX <sup>5</sup> , VA, WA did not list any specific staff training topics Source: FY05 FTF Grant Reports (2006 Annual – 2008 Final)			

Although grantees did not consistently specify the topics of trainings for families and professionals, the training topics they did specify covered a broad array of content areas, as shown in Table 6, below.

<sup>4</sup> NH did not complete their Emergency Preparedness and Special Needs training before the end of the grant period.

<sup>5</sup> TX listed numerous trainings under development in the 2006 Annual Report; however, it is unclear if these trainings were finalized or conducted. Over the course of the grant, TX developed 17 trainings.

**Table 6. FY05 FTF Grant Training Topics for Families and Professionals**

Training Topics	CT	ID	MI	NH	RI	SC	TX	VA	WA
Health insurance and health care services	X	X	X		X	X			
Medical home			X				X	X	
Resources for parents (for P2P information sharing)			X			X			X
Health care financing	X								X
Supporting the integration of CYSHCN in community-based activities, including health care & emergency services				X			X		
Consumer directed services (e.g. Medicaid waivers)							X	X	
Special education			X					X	
Health education		X	X						
Transition			X					X	
Parent leadership		X		X					
School-based medical services		X							
Understanding state or federal policies or rule changes	X	X							
Accessing mental health services			X						
Training based on Resource Toolkit	X								
Youth substance abuse prevention			X						
Advocacy							X		

Source: FY05 FTF Grant Reports (2006 Annual – 2008 Final)

**Technical Materials**

One grantee’s (CT) technical materials included a PowerPoint presentation about the legislative processes and civic engagement. Another grantee (NH) also developed fact sheets about obtaining goods and services through Medicaid. Other technical materials reported include updates to databases to enable better tracking of families and follow up (SC), and frequently asked questions sheets and checklists for understanding Medicaid and school-based services (ID).

**Reports or Analyses of Issues or Specific Topics**

Four grantees (CT, ID, NH, and VA) noted that they produced reports or analyses. These included sheets about health care financing (state-specific insurance, Title V,<sup>6</sup> private insurance, and Supplemental Social Security) (CT), results of a survey of families needs for information and referral, particularly regarding medical home and transitions (NH), and a report on oral health (VA). Other grantees (RI, SC, and TX)

<sup>6</sup> Title V of the Social Security Act assures Federal support of State efforts to support health and welfare of mothers and infants. States apply to MCHB/HRSA annually for Title V funds through Maternal and Child Health Block Grants. Title V-funded programs provide direct care services, enabling services, preventive services, or infrastructure-building activities to improve maternal and child health. States must spend 30 percent of their Title V Block Grant funding on CYSHCN. See also <http://mchb.hrsa.gov/about/understandingtitlev.pdf>.

also produced analyses of issues and specific topics, which they may have considered to be outreach or educational materials.

### New Policies

Four grantees (NH, RI, SC, and VA) reported that they helped implement new policies. Two grantees (RI and NH) worked with their respective State Medicaid agencies to develop criteria for standards of care and eligibility guidelines under the Katie Beckett provision of Medicaid for children and youth with special health care needs. Another grantee (SC) worked to pass state legislation requiring that insurance companies provide reimbursement for Applied Behavioral Analysis (ABA) therapies and to increase SCHIP eligibility. Both of these efforts led to increased access in services, which the grantee described as enduring changes, which will be discussed in the next section of this report. A fourth grantee (VA) worked with their State Medicaid agencies to add consumer-directed services to state DD and MR waivers. Although these four grantees were the only grantees to report new policies as an output, several other grantees (CT, ID, TX, and WA) discussed policy efforts in other areas of their reports.

### Changes Produced

The Final Report asked FTF grantees to summarize the enduring changes in long-term care legislation, policies, programs, processes, or practices that have occurred during the grant period that resulted, either directly or indirectly, from the grant. Table 5 below summarizes findings from FTF grantee Final Reports, however, the data reveal that there is overlap in how grantees interpreted the categories of “access” to services and “availability” of services. Grantee efforts that increase the availability of services for CYSHCN are likely to result in greater access to services and, understandably, the grantees’ categorization of their changes as related to either access, availability, or both, is somewhat arbitrary. The data in Table 7 and the supporting examples reflect the grantees’ own categorizations of the outcomes of their efforts. In addition to the changes produced cited by grantees in their Final Reports, grantees were also asked to provide information on a semi-annual basis on impacts, outcomes, and accomplishments.<sup>7</sup> Culminating information from the Final Reports on impacts, outcomes, and accomplishments is provided for each grantee in the Appendix of this report.

**Table 7. Changes produced by FTF Grantees**

Type of Change Produced	CT	ID	MI	NH	RI	SC	TX	VA	WA
Access		X			X	X	X		X
Availability of Services	X			X	X	X			
Consumer Direction and Control	X	X		X	X		X	X	X
Quality					X	X			
Other	X		X		X				X

Source: 2008 Annual (Final) FY05 FTF Grant Reports

<sup>7</sup> FY05 FTF grantees were not required to hire local evaluators or create a formal evaluation plan, however, “Impacts,” “outcomes,” and “accomplishments” were discrete fields in the dehpg.net Semi-Annual/Annual and Final Report templates. Although the dehpg.net reporting instructions provided some guidance on the definitions of these terms, grantees’ interpretations of what comprised an impact vs. and outcome vs. accomplishments were varied. The information in the Appendix reflects the grantees’ categorization of their results as reported in the Final Reports.

## Access

Many grantees reported that they improved access to services by hosting trainings and conferences, attending community events, and sending out information through broadcast emails and newsletters about home and community-based services. One grantee (WA), for example, worked with the Hispanic community to help them better understand how to access Medicaid benefits. Several grantees that reported improved access through trainings and educational outreach asserted that the knowledge shared with their target audiences would persist after the end of the grant period. Other grantees approached access through advocacy and policy initiatives. For example, one grantee (WA) engaged policy leaders to emphasize the need for aged care and supports for CYSHCN. Another grantee (SC) engaged in advocacy efforts, which led to several reported improvements to access including; public/private insurance model; a rule change that allowed children with autism to receive coverage for Applied Behavioral Analysis (ABA) therapies; prevention of budget cuts for services important to CYSHCN; and an increase of SCHIP coverage from 150% above the Federal Poverty Level (FPL) to 200% above FPL.

## Availability of Services

As noted previously, grantees' categorization of outputs related to availability of services vs. access to services is not always clear cut. For example, in CT, the grantee advocated that the Legislature authorize a Catastrophic Medical Expenses Fund to pay for medical expenditures that cost more than a specified percentage of a person's family income.<sup>8</sup> By making medical care more affordable, children may have had increased access to care, and certain services may have become more available. Another grantee (NH) was influential in making emergency preparedness officials aware of children with special health care needs, and services for this population are now more likely to be available during an emergency. Another grantee (RI) also supported the development of new services, such as Home Based Therapy Services (HBTS), Personal Assistance Service and Supports (PASS). Additionally, the grantee assisted in the development of a Medicaid waiver for respite services for caretakers of children and youth with special health care needs.

## Consumer Direction and Control

Seven of the grantees (see Table 7) reported changes related to consumer direction and control; however, grantees interpreted "consumer direction and control" in two different ways: 1) an orientation toward delivery of HCBS that allows for informed consumers (as individuals or through representatives) to make choices about services they receive, the manner in which they receive them, and the individuals from whom they receive them<sup>9</sup> and 2) consumer engagement and awareness of their options for medical care and social services. Among the grantees that followed the former definition, one grantee (TX) used their conferences, trainings, newsletters, and list serves to make parents aware of consumer directed services through the Medicaid waiver programs. A second grantee (VA) worked with the state Medicaid agency on adding consumer-directed services to the states' MR and DD waivers.

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<sup>8</sup> (2010, March 15). OLR Bill Analysis: sHB 6152. An Act Establishing a Medical Expense Pool, archived at <http://www.cga.ct.gov/2009/ba/2009HB-06152-R000315-BA.htm>.

<sup>9</sup> National Institute of Consumer-Directed Long-Term Care Services (1996). *Principles of Consumer-Directed Home and Community-Based Services*. Funded by a grant to the National Council on Aging and the World Institute on Disability, and sponsored by the Administration on Aging and the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.

The grantees that interpreted consumer direction and control more broadly to mean consumer or family engagement or awareness reported changes resulting from families' involvement on a Medical Home Advisory Board, dissemination of fact sheets about the Katie Beckett waiver, and advocacy efforts that focused on the special healthcare needs of children during emergencies. One grantee (NH) reported that families who participated in a training program reported being better equipped to actively engage with the local community and medical community for their children with special medical needs.

### **Quality**

Two grantees (RI and SC) reported improvements to the quality of medical care and services provided to CYSHCN and their families (see Table 7). The grantee in RI worked with Medicaid and Title V agencies to adopt quality assurance mechanisms to monitor the delivery and quality of services and supports for CYSHCN and their families. In one state (SC), the grantee formed relationships with pediatric practices, including the state's largest children's hospital, to increase the role of parents as advisors to medical and hospital management staff, and facilitate opportunities for parent-to-parent education. The grantee reported that these efforts improved the care that was provided.

### **Other**

Other types of changes that resulted from the FTF grant were that community leaders were trained in helping families of CSHCN become more aware of health insurance options, community and professional networks were expanded, there was increased stakeholder engagement in Title V CSHCS strategic planning, increased coordination between care providers, and understanding of consumer needs. For example, one grantee (WA) promoted the benefits of Medicaid buy-in as a part of the Family Opportunity Act, which supported the reauthorization of the CHIP Program. In Michigan, the grantee participated in the Title V CSHCS strategic planning process.

## IV. Summary and Conclusions

### Common Barriers and Challenges to Implementation

#### Contextual Challenges Cited By Grantees

Grantees reported numerous contextual challenges that prevented or impeded their efforts to effect systems-wide change, and even accomplishing all of their objectives. Lack of funding and the state fiscal environment were the most frequently cited contextual challenges. Some grantees said that their states had unprecedented state budget cuts, which invariably had a negative impact on the available funds for social services. The families targeted by the grantees' programs also faced challenges, including bankruptcy, foreclosure and homelessness, all of which required services, such as case management, that went beyond the scope of this grant. Grantees also reported insufficient accessible transportation and housing (CT), limited waiver options for children (CT), gaps in access health and LTC services, workforce and lack of access to medical care, and insufficient grant funds were also cited. Table 8, below summarizes the contextual challenges that grantees reported over the course of the 3-year grant period.

**Table 8. Contextual Challenges Described by FY05 FTF Grantees\* over Entire Grant Period**

Contextual Challenges	CT	ID	MI	RI	SC	TX	VA	WA
Health care and LTC service gaps (e.g. DSW shortage, lack of access to care in rural areas)	X			X			X	X
State fiscal environment		X	X	X				
Families' needs went beyond scope of grant	X			X		X**		
Infrastructure gaps (e.g. accessible housing, transportation)	X							
Limited HCBS options (e.g. waivers)	X							
Lack of or fractured parent networking systems		X						
Stakeholders excluded from Legislature's decision making process				X				
State-specific policies	X							

\*NH, WA did not report specific contextual challenges.

\*\*TX reported that an increased number of new parents contacting the grantee stretched the FTF's capacity.

Source: FY05 FTF Grant Reports (2006 Annual – 2008 Final)

#### Project Implementation Challenges Cited By Grantees

As shown in Table 9, below, project implementation challenges reported by grantees included staff turnover (e.g. project directors and health information specialists), limited time for hired staff to work on the grant, troubles with partners, changes in scope of the grant after it had been awarded, the competing demands of their target populations, technical troubles with web-based reports and dissatisfaction with technical assistance (TA) providers and Ascellon, the TA referral group.

Four states (CT, ID, RI, and VA) were challenged by high levels of staff turnover, and one (WA) complained about the instability of staffing of their TA provider. One grantee (RI) was not able to hire a staff member to work exclusively on the FTF grant until May 2006, and therefore could not spend grant funds until that time. Another grantee, (ID) hired five project directors over the course of the grant, and with each hire and departure the make-up of their Advisory Board changed. Staff turnover was also a problem with grantee’s partner organizations, which negatively affected collaborative efforts.

**Table 9. Project Implementation Challenges Described by FY05 FTF Grantees**

Project Implementation Challenges	CT	ID	MI	NH	RI	SC	TX	VA	WA
Staffing challenges (e.g. hiring delays, turnover, lack of staff with appropriate skills)	X	X			X	X		X	
Challenges with state agency and community stakeholders and grant partners		X	X	X				X	X
Grant scope (initial plans proven infeasible)								X	X
Problems with web-based reports							X		
Problems/turnover with TA providers and grant monitoring							X		X
Families’ time limits (e.g. couldn’t attend trainings)				X					

Source: FY05 FTF Grant Reports (2006 Annual – 2008 Final)

Seven of the grantees (CT, ID, MI, NH, RI, VA, and WA) described the ways in which they addressed the contextual and project implementation challenges summarized in Tables 8 and 9. Adaptations included moving training locations to be more accessible, challenging the Legislature on proposed policy changes, and finding new partners and funds to sustain grant activities. One grantee (MI) relied on in-kind support to address funding shortages and another grantee (VA) applied for new grants to sustain the health information center. A third grantee (ID) worked to build new parent support groups and working to increase the collaboration between existing groups to address the fractured nature of the state’s parent advocacy groups. Additionally, a fourth grantee (CT) encouraged families write about how proposed legislation would negatively impact them, and after being presented to the Legislature, the rule changes were not passed.

## Recommendations

The Final Annual Report allowed grantees to provide feedback, in the form of recommendations, to state and federal policy makers. These recommendations are listed by grantee in Table 10, below. Two states (TX and VA) opted not to provide such recommendations. Six grantees (CT, ID, MI, NH, RI, and SC) provided recommendations for policies at the state level, while only one grantee (WA) made recommendations to federal policymakers. Grantees’ recommendations varied widely and there are no commonalities between them.

**Table 10. FY05 FTF Grantee\* Recommendations to State and Federal Policymakers**

Recommendations to Policymakers	CT	ID	MI	NH	RI	SC	WA
<b>State-level</b>							
Invest in accessible infrastructures (e.g. housing and transportation)	X						
Provide permanent funding for FTFs			X				
Protect services for CYSHCN from budget cuts						X	
Mandate stakeholder involvement in policy changes					X		
Institute more comprehensive waiver for children	X						
Increase state agency collaboration				X			
Conduct cost studies		X					
<b>Federal-level</b>							
Reimburse for systems of care instead of fee-for-service							X
Increase continuity of care within waiver programs and across states							X
*VA, TX did not report specific recommendations.							
Source: 2008 Annual (Final) FY05 FTF Grant Reports							

With the 2006 passage of the Family Opportunity Act (FOA) under the 2005 Deficit Reduction Act, primary funding support for the Family-to-Family Health Care Information and Education Centers was transferred back to the Maternal and Child Health Bureau, Health Resources and Services Administration. Family-to-Family Health Care Information and Education Centers now exist in all 50 states and the District of Columbia. Although no longer under the administration of CMS, there are a few ways, aside from continued funding, that the FTFs can be supported nationally:

- Foster collaboration and information sharing between FTFs and Aging and Disability Resource Centers (ADRCs). ADRCs have been supported by Administration on Aging (AoA) and CMS and provide a similar set of information and referral services, primarily to adults with disabilities and elders, through single points of entry in 49 States and territories as of September 2009;
- Require annual reporting on a consistent set of measures that will allow grantees to monitor their progress in achieving desired outcomes over time; and
- Require that FTFs hire local evaluators to assist them in reporting on this national set of measures and also to provide information needed for continuous quality improvement and data to support applications for supplemental funding.

## Conclusions

Based on the information provided in their web-based reports, the FY05 FTF grantees were able to accomplish a great deal to establish and expand information networks for CYSHCN and their families within their states. In addition to providing guidance to individual families, grantees held trainings, distributed outreach and educational materials, wrote reports and created technical materials, and contributed to new policies. Grantees reported enduring changes in the areas of access, service availability, consumer direction and control, and quality. Grantees conducted and unanimously reported completion or scheduled completion of activities in spite of implementation challenges ranging from FTF staff turnover to difficulties with partners and TA providers and contextual challenges such as shortfalls in provision of basic services and gaps in availability of care. Continued Federal support of FTF efforts can help ensure that children and youth with special health care needs and their families have access to the information they need to make informed decisions about health care and home and community-based services.

# Appendix

# Connecticut

<b>Title of Grant</b>	Connecticut Family-to-Family Health Information Network
<b>Name of Grantee</b>	FAVOR, Inc.
<b>Subcontractor(s)</b>	None.

## Goals and Objectives

- Develop the Connecticut Family-to-Family Health Information Network and promote the Network across the State.
- Provide training, advocacy, and support to Connecticut families of CSHCN.
- Provide information and resources to providers.
- Develop policy responses to issues identified by families of CSHCN in Connecticut and implement a policy agenda.
- Review data on project activities (e.g. trainings and meetings)

## Activities

- Hire staff and Health Information Specialists.
- Convene monthly management meetings.
- Develop and disseminate materials.
- Convene quarterly meetings of the Family-to-Family Grant collaborators, regional medical homes, and others to discuss system issues related to the delivery of health care to Connecticut's CSHCN.
- Provide training to advocates around the state, to support groups that exist, so families have a wide network to turn to when the need help solving health issues.
- Develop intake form and toolkit.
- Provide training to families.
- Disseminate and toolkits to providers.
- Review data and summaries of trainings management meetings and other anecdotal data to formulate a legislative agenda annually.
- Mobilize support for a legislative agenda.

## **Reported Impacts, Outcomes, and Accomplishments**

### ***Impacts:***

- Collected data regarding families' issues with medical insurance and prepared report for the Family Support Council to be addressed on the Council's legislative agenda.
- Shared data with other groups in CT.

### ***Outcomes:***

- 3 HIS have worked to solve health, insurance & educational issues. They have assisted families in finding funding sources, getting on assistance, worked with Title V, Family support Council, & current legislative issues around the state.

### ***Accomplishments:***

- Over 300 families received help in learning the systems they need to use to get services, and had questions answered.
- Over 150 calls from agencies, non-profits and schools were taken with information and resources shared to help families they were serving.
- A connection to Husky (state Medicaid program) was strengthened and resources were shared with families they were serving, while they helped us with Husky changes and keeping our info current.
- Materials were developed and edited over time to be distributed at events to help keep families organized and up to date.
- Families were instrumental in preventing a change in school exit age, preventing cuts in services to age 21 grads, getting their voices heard on Husky changes, and learning how important their family stories are in educating legislators about needed changes and service gaps.

# Idaho

**Title of Grant** Idaho Family-to-Family Health Care Information and Education Center

**Name of Grantee** Idaho Parents Unlimited, Inc. (IPUL)

**Subcontractor(s)**

- Consultant for graphics design and editorial/content writing for newsletter
- Evaluation consultant
- Database consultant/contractor

**Goals and Objectives**

- Establish a sustainable, centralized statewide Family-to-Family Health Information Center based on identified needs.
- Provide outreach, dissemination of information, education, and training to families of CYSHCN.
- Create an infrastructure for collaboration and sustainability by developing new family and interagency relationships and strengthening the existing ties with community-based local, state, and national partners.
- Increase medical access/coverage for children under the CSHP area in Idaho. Stop discrimination under private insurance in Idaho for CSHP children. The goal is to make (at least) one rule change.

**Activities**

- Hire a project director and set up job functions.
- Identify and recruit families of CYSHCN who want to be a part of the Family-to-Family Advisory Council, as well as key stakeholders/professionals who serve CYSHCN and want to be a part of the Advisory Council. Identify long-term strategies for sustainability by working closely with the Advisory Council.
- Identify and utilize the experiences of other funded Family-to-Family Health Information Centers across the State to help ensure that Idaho’s plan stays on track and learns from prior experience.
- Establish a toll-free telephone line for CYSHCN and their families.
- Develop and disseminate information statewide about the Family-to-Family Health Information Center in Idaho via various marketing methods.
- Review and enhance the Medical Home of Idaho information to include a Family Module that is easily accessible on the Web.
- Provider healthcare information, training, and resources to families and providers.
- Establish a statewide network for families to share information and support and provide health care information, training and resources to families and providers.
- Coordinate every-other year all IPUL staff including: PTI/VSA arts and IHRC staff conference with HIC track.

- Collaborate with existing Family-to-Family Health Information Centers and other resources on best practices and lessons learned in providing services to CYSHCN.
- Partner with other national, state, and local family organizations working with CYSHCN to identify ways to facilitate effective systems change and look for additional partnerships (i.e., immigration agency, foster care, adoption agencies that provide placement for CYSHCN).
- Serve as a clearinghouse for state-level organizations that are seeking family involvement for program and policy development and conferences. Work with families to mentor them into these roles through various family leadership skills development workshops or trainings.
- Identify long-term strategies for sustainability by working closely with the advisory council to identify short-long term objectives to meet this goal.
- Obtain ongoing feedback through the Advisory Committee and community partners to identify emerging needs, gaps and directions for the future.
- Collaborate with Consortium for Idahoans with Disabilities to educate policy-makers about the needs of children and adults with special health care needs and their families.
- Continue and enhance collaboration with Idaho Medicaid and CSHP Office.

## **Reported Impacts, Outcomes, and Accomplishments**

### ***Impacts:***

- None reported.

### ***Outcomes:***

- Identify areas to improve access and/or coverage for CSHP children. New language was developed to increase private insurance coverage for children. New Permanent Rules were introduced to the Committee on Commerce and Labor in the new session. The rules passed uncontested.
- To increase the flexibility and choice and to expand upon existing resources for families in providing health care for children with special health care needs by helping Idaho to implement Family Directed Services under Medicaid.

### ***Accomplishments:***

- Created an Advisory Council, a web site and marketed our 1 800 numbers for the F2F grant across the state of Idaho.
- Trained multiple staff members on the current medical systems in Idaho.
- Published 5 issues of the Parent Network Newsletter including Health information and sent each issue to over 9,000 Idahoans.
- From October 2006 to September 30th 2008 IPUL carried out 37 outreach activities in which F2F materials and information were distributed.
- 627 parents and professionals were contacted and educated about the needs of CYSHCN through these outside agency events.
- Provided one-on-one assistance to parents and professionals for children with health related issues through 2,714 telephone and e-mail contacts over the past three years.

- Participated in over 90 state and local meetings that focused on gathering information and data about health and disability related issues in Idaho in order to inform decision making in the future.
- Developed working relationships with key stakeholders throughout state government in and supported them in making decisions making about health and disability services.
- Created public awareness materials, educational materials, documented system-wide problems and identified key leaders in state government to assist us in future work for CYSHCN.
- Worked to make materials culturally competent by translating many of those materials into Spanish.
- Adapted our database to collect and report on Family to Family Health Education Center activities.

# Michigan

**Title of Grant** Family-to-Family Health Care Information and Education Center  
**Name of Grantee** Southeast Michigan Health Association Family Center for Children and Youth with Special Health Care Needs

## Subcontractor(s)

- Association for Children’s Mental Health
- Citizens Alliance to Uphold Special Education (CAUSE)
- New Center Community Mental Health
- Henry Ford Hospital
- Devos Hospital

## Goals and Objectives

- Provide information to increase access to and utilization of coordinated, ongoing care in a Medical Home, and health care and public health insurance for families of CSHCN.
- Increase outreach, training, and parent-to-parent support to underserved populations receiving special education and early intervention services and physicians who treat CSHCN.
- Increase and coordinate the dissemination of information on resources and services to families of children with genetic conditions, birth defects, and mental illness. Provide information on transitioning to adult health care, work, and independent living for CSHCN and their families.
- Ensure that families of CSHCN develop effective partnerships with service and health care providers, and that they are satisfied with the information, supports, and services that they received.
- Improve access to quality care and supports for children and youth with special needs in their communities by empowering families with information, training and support.

## Activities

- Coordinate Michigan Medical Home Training with representatives from Henry Ford Hospital, DeVos Hospital, members of the Michigan Chapter of AAP and the Great Start Initiative.
- Develop, print, and distribute Medical Home Information to primary care providers during Henry Ford, DeVos and other trainings coordinated through the grant.
- Implement the usage of electronic care plans by care managers within the Henry Ford Health System. Track the number of managers trained and the number of plans developed.
- Establish a Medical Home Training Module in the CSHCS On-line Training Course.
- Begin training Families with Special Needs (FSN)/Health Resource Center (HRC) Parents on Medical Homes using the Medical Home Training Module.

- Utilize the Parent Participation Program (PPP) /Family Center for Children with Special Health Care Needs Lending Library to increase families about health care and public health insurance options. Distribute information about the library through the Family to Family Web site and grant trainings.
- Conduct a web search to learn about national resources and share information with partners. The Family Center Resource Specialist, project manager, and project director be familiar with resources available to families through the internet, interagency workgroups, and other collaborative activities. Staff will receive regular resource updates through Family Voices. Information will be posted to the F2FHIEC website and shared with families and partners through mass email, listserv postings, and traditional mailings on various topics, including transition, prescription assistance, and special education.
- Make families and providers aware of public health insurance options through Public Health Insurance on-site and on-line training modules, incorporating MiChild and Healthy Kids Pages into the Watch Me Grow Calendar, and distributing a public health insurance options booklet for families and physicians at conferences, meetings and through individual requests.
- Begin providing support and training to families regarding Health Care and Public Health Insurance Options.
- Formalize/coordinate parent outreach, training and support system for families receiving special education and Part C services by offering a Health Education training in collaboration with CAUSE, the state parent training center, and participating on special education committees, such as the Early On Parent Involvement Committee, which is comprised of state and local parent leaders.
- Increase the number of families trained to provide health care information and support to other families by offering 4 Health Resource Support Parent Trainings.
- Raise awareness to the Health Information and Education Center's existence through listservs, mass emails, presentations, and information sharing with partners.
- Partner with the Genetics Resource Center; promote their website through presentations, trainings, committees, and outreach materials; involve their parent consultant in collaborative program activities; and link the Genetic Training Module to Project Modules.
- Develop a protocol to assure uniform provision of information to families including CSHCS/FSN and other literature.
- The Association for Children's Mental Health (ACMH) will develop 2 training modules.
- ACMH will deliver modules to families and professionals in five communities.
- New Center will increase the skills of professionals and families caring for children with mental illness during four annual sessions in Wayne County using a Project Resilience Model. Sessions were held in November, March, July and September during FY 2006 – 07.
- ACMH will develop web-based training modules for "How to Access Health Care Coverage for Children with Mental Illness" and "Is Your Teen Ready for Adult Life."
- PPP will collaborate with the CSHCS Transition Analyst to address transition issues through consultation, presentations, and training opportunities and with major hospitals implementing medical home models for youth in transition i.e. Henry Ford and DeVos.
- PPP will collaborate with the Michigan DD Council and participate on health and parent committees and with representatives from SSA through trainings, presentations, and partner information sharing.

- PPP will develop a formalized system of intake and referral for families seeking information and education related to guardianship options to the Michigan Protection and Advocacy Services.
- PPP will collect, store and disseminate information on issues related to home and community based supports. Parent leadership materials will be inventoried in the library and a Library Usage Evaluation will be developed and disseminated.
- PPP will establish and implement an information, referral and tracking database called BPCT.
- PPP will measure the project's effectiveness in assisting families to gain access to information, supports and training. The PPP Intake, Referral, and Follow-up Coordinator will utilize the database to follow-up with families regarding their usage of the Family Phone Line and other HRC services and will hold a meeting to discuss progress in meeting grant goals and objectives.

## **Reported Impacts, Outcomes, and Accomplishments**

### ***Impacts:***

- More families and children/youth with special needs have access information and services needed to improve functioning and remain in the community.

### ***Outcomes:***

- An information and referral system that is effective at connecting families, children and youth with special needs to available health care and support services.

### ***Accomplishments:***

- Staff from the F2FHIEC, the Michigan Department of Community Health Hereditary Disorders Program, Spectrum Health and Henry Ford Health System collaborated on the development of an online Medical Home Training Module and other medical home materials.
- Families with CSHCS received health care and public health insurance information through the Center's trainings and outreach activities in conjunction with grant partners.
- Free and Low Cost Public Health Insurance booklets were translated into Spanish and Arabic.
- In partnership with CAUSE, held health/education trainings for families of CYSHCN to help them advocate for their children's education.
- Trained families and professionals on transitions through HRSP training, Health/Education training, and from the Transition Specialist.

# New Hampshire

**Title of Grant** New Hampshire Family-to-Family Health Care Information and Education Center

**Name of Grantee** New Hampshire Coalition for Citizens with Disabilities

**Subcontractor(s)**

- Curriculum development, outreach, and translation consultants from Minority Health Coalition, National Family Voices Staff

**Goals and Objectives**

- Develop an educational training curriculum for family leaders and families that includes current recommended practices to support full inclusion of CYSHCN in community activities and services, and to the extent possible, is evidence based.
- Establish a network of trained family leaders (at least one from each of the state's nine counties) to provide ongoing training, TA and support to families in their areas, in partnership with NHFV.
- Identify and implement strategies to sustain the network after the project is completed.
- Provide training to at least 675 families of CYSHCN (25 per county/year) of CYSHCN via education, training, technical assistance, support and information dissemination to families and providers.
- Provide technical assistance, support and information to at least 2025 families of CYSHCN (75 per county per year). (To be implemented by family leaders with TA and support from NHFV).
- Develop and/or strengthen collaborative partnerships with agencies, programs, and representative providers that play a role in developing and implementing healthcare policy for CYSHCN through stakeholder outreach efforts.
- Increase awareness of NHFV services through a public awareness campaign targeted at identified populations (grandparents, culturally diverse, and families receiving SSI).
- Identify and implement strategies to sustain the outreach/TA and support to specific populations following the completion of the project.
- Evaluate the process and outcomes according to the evaluation plan.
- To assist families of CYSHCN in their efforts to raise their children within their local communities, as defined by the family and youth.

**Activities**

- Review relevant literature and existing materials related to Individual Healthcare Plans (IHPs), Emergency Healthcare Plans, and other pertinent topics.
- Based on the results of the previous activity, generate an outline of content areas, checklists and other material to be included in the curriculum.

- Survey community service providers, along with a random sample of the 2,000 families from the New Hampshire Family Voices (NHFV) database, and families identified through liaisons with Minority Health Coalition, AARP, and other venues to identify priority content for the curriculum.
- Work with the Minority Health Coalition to assure that the curriculum and materials address the needs of diverse families.
- Work with Partners in Health (PIH) to determine the feasibility of PIH coordinators serving in the capacity of family leaders on a long-term basis, or at a minimum, assisting the project in identifying potential family leaders in their areas and providing ongoing support.
- Train at least nine family leaders, one from each of New Hampshire's nine counties, who will then provide training and offer support to families in their areas.
- Identify and implement procedure for the networks operation, including communication (e.g. listserv, quarterly meetings) ongoing access to current/best practice information, logistics, documenting costs/needed resource, delivering TA and support, documenting outcomes and effectiveness, etc. .
- Utilize NHFV's advisory committees and state partnerships to identify and implement strategies at the state, regional, and community levels.
- Implement evaluation activities and procedures as specified in the evaluation plan.
- Determine/advertise training sites & dates (2 per county per year).
- Develop and disseminate to participants registered for the training an introductory packet with pre-training evaluation.
- Advertise the availability of TA and support via PIH, Parent-to-Parent NHFV and other venues.
- Provide individualized TA and support according to procedure developed.
- Identify or generate appropriate family-friendly information on issues/topics related to CYSHCN (e.g. fact sheets on accessing home and community based Medicaid waivers; links to good websites, policy briefs, expanding NHFV website, etc.).
- Disseminate information through a variety of venues (NHFV website, website links, during training sessions, in partnership with other organizations mailing information to families, etc.).
- Work with family leaders and partner organizations to identify and implement strategies to sustain these efforts at the state and regional/local levels.
- Implement evaluation activities according to the evaluation plan.
- Identify community organizations, agencies, programs, and representative providers working with grandparents raising CYSHCN.
- Identify community organizations, agencies, programs, and representative providers working with families of diverse cultural or ethnic backgrounds who have CYSHCN.
- Collaborate with Title V, CYSHCN program, and SSI Outreach Coordinator to develop outreach to families receiving SSI benefits to enhance access to information and education.
- Develop and disseminate printed materials (brochures, PSAs, etc.) for use as outreach to target populations.
- Launch public awareness campaign via media, printed materials, PSAs, etc.

- Work with project partners and the Family Resource Connection to generate and implement strategies to sustain dissemination and outreach efforts.
- Implement evaluation activities and timelines according to the plan.

## **Reported Impacts, Outcomes, and Accomplishments**

### ***Impacts:***

- Reviewed 4 documents for NH Medicaid & RFP for statewide incontinence supply vendor.
- NHFV reviewed materials for both services providers and families.
- Had 140,029 hits on Web site and 704 calls to the 1-800 number.
- Supplied people with 8,708 pieces of written information.
- Provided training to 62 individuals.

### ***Outcomes:***

- Developed an educational training curriculum for family leaders and families that includes current recommended practices to support full inclusion of CYSHCN in community activities and services.
- Trained at least 9 family leaders, one from each of NH's nine counties who will then provide training and offer support to families in their areas.
- Identified or generate appropriate family-friendly information on issues/topics related to CYSHCN.
- Increased awareness of NHFV services through a public awareness campaign targeted at identified populations (grandparents, culturally diverse, and families receiving SSI).

### ***Accomplishments:***

- Established new and strengthened existing relationships with other state agencies, family organizations and potential funders. Many of these relationships have resulted in funding for NH Family Voices to continue statewide efforts for families and children with special health care needs.
- Developed materials such as the Emergency Preparedness "To Go Kit" and Emergency Evacuation Plans at schools for Children with Physical Disabilities became the impetus for a strengthened relationship with Homeland Security and NH Dept of Safety as they consider ways to meet the needs of Families of Children and Youth with Special Health Care Needs in NH during emergency situations.
- Held community based training to support the integration of a CSHCN into community based activities by outlining a health plan and an emergency health plan to support families in integrating their children into local activities.
- Educated professionals and volunteers about CYSHCN and the steps to be taken in the event to a health problem.
- Equipped families to engage with their local and medical communities to develop health care plans for their children with special medical needs to allow the children to participate in community activities.

# Rhode Island

**Title of Grant** Rhode Island Family-to-Family Health Care Information and Education Center

**Name of Grantee** Rhode Island Parent Information Network (RIPIN)

**Subcontractor(s)**

- Evaluation consultant

**Goals and Objectives**

- Increase leadership capacity to promote effective and enduring improvements in community long-term support systems.
- Contribute to the understanding of effective and efficient methods of accessing quality and appropriate services and supports.
- Promote knowledge about and opportunities for family and professional partnerships in policies and practices related to individual and family-directed supports within integrated community settings.
- RIPIN will expand the development/dissemination of information to families of children and youth with special health care needs; provide education /training to effectively navigate the system of care and promote the philosophy of family-centered care.

**Activities**

- Review Rhode Island Parent Information Network (RIPIN) workshop materials specific to CYSHCN.
- Promote RIPIN and other workshops to audiences of the Family-to-Family Health Information and Education Center.
- Develop training materials to address health care financing, medical homes, leadership, and advocacy.
- Provide technical support, as requested, to families and professionals working with them.
- Provide information about health, health insurance, family support, diagnosis specifics, public and private programs, policy and legislative updates, medical homes, early screening and intervention, and access to services and supports .
- Enhance and expand the ongoing development of the statewide peer-to-peer network, Family-to-Family Network of Rhode Island.
- Increase attendance/participation at conferences and fairs by providing program brochures, newsletters, and other timely information.

## **Reported Impacts, Outcomes, and Accomplishments**

### ***Impacts:***

- Created a training curriculum in Spanish and English.
- Provided technical assistance for families and providers on access to public and private programs/community services.
- State-wide, provided a toll free telephone number and resource packets for families, professionals and other interested stakeholders.

### ***Outcomes:***

- Families of children and youth with special health care needs will have improved access to information on public and private programs/community services.

### ***Accomplishments:***

- In this final reporting period (10/01/05 - 09/30/2008) had 661 family members and professionals attend the RIPIN workshops.
- RIPIN received 2,539 requests to obtain the workshop schedule for distribution.
- Provided education, training and support to 7,671 individuals, including service coordinators, service providers, social workers, special educators and family members of children and youth with special needs.
- Currently have 112 members participating in the statewide peer to peer network that is available for both English and Spanish speaking families. This network provides an online opportunity for families of children and youth with special needs to connect with one another to share experiences, information and support.
- Hosted a one day family/professional conference in each of the three years of the grant with more than 490 participants in total. The goals of the conferences were to provide education and information on programs and policies impacting families and providers, to educate family members and professionals on available resources, services and supports, and to demonstrate and promote family/professional partnerships at work throughout Rhode Island.
- Reached out to 17,815 family members and professionals.

# South Carolina

**Title of Grant** Family-to-Family Health Care Information and Education Center for South Carolina

**Name of Grantee** Family Connection of South Carolina, Inc. (FCSC)

**Subcontractor(s)**

- Web site developer consultant
- Evaluation consultant

**Goals and Objectives**

- Develop the capacity of the statewide Family-to-Family Health Care Center.
- Provide technical assistance (TA) and facilitate peer-to-peer TA of varying intensity and duration, including information, referrals, and short-term assistance.
- Collect, store, and disseminate information on issues relevant to home and community services and supports, local providers, philosophy of consumer and family-directed care, medical home, and health insurance.
- Develop and disseminate original materials to assist CSHCN and their families, providers, and other stakeholders with the goal of meeting identified needs or gaps in available materials.
- Provide input and feedback to CMS, state agencies, and existing Family-to-Family Centers on Family Connection of South Carolina, Inc.'s (FCSC's) ongoing operations and training activities. Identify barriers that will impact future policy decisions and update CMS with reports.
- Improve access to quality care and supports for children and youth with special health care needs in their communities by empowering their families with information and advocacy.

**Activities**

- Establish project management.
- Train at least 120 parents as volunteer Health Care Resource parents.
- Provide peer-to-peer telephone, e-mail, and in-person TA.
- Present at Hopes and Dreams Conference.
- Develop methods of data collection and train staff.
- Collect and disseminate relevant information and resources.
- Identify gaps in available materials, develop, and disseminate additional materials.
- Provide reports on project activities to CMS and project partners.
- Provide information on barriers and recommendations for change to CMS and relevant state agencies.
- Participate in opportunities for exchanges between Centers.

## **Reported Impacts, Outcomes, and Accomplishments**

### ***Impacts:***

- A larger proportion of children and youth with special health care needs and their families will access the information and services needed to improve functioning and remain in the community.

### ***Outcomes:***

- An information and referral system is effectively connecting more families of children and youth with special health care needs to health care, community services, and supports.

### ***Accomplishments:***

- Placement of parents in pediatric practices and began to develop a culture of acceptance for parents' expertise.
- Facilitated parent-to-parent support in Neonatal Intensive Care Units.
- Increased the participation of parents on multiple state committees.
- Educated parents on the benefits of advocacy, which resulted in legislative changes that increased access to and quality of care (Ryan's Law for children with autism, increase of SCHIP, maintained the integrity of the Department of Disabilities and Special Needs).
- Hosted the Family Connection Academy and trained a diverse group of 32 parents from across SC to serve as volunteer leaders.
- Hosted two statewide conferences that had an average attendance of nearly 310 individuals.
- Increased the organization's capacity to track meaningful outcomes by enhancing the data collection materials.
- Produced and distributed resources including a Resource Brochure, Welcome Packet, and Insurance Module.
- Provided parent-to-parent support to 5,259 parents, siblings, or grandparents.
- Trained 217 parents to become Health Care Resource Parents.
- Improved the website and display boards.

# Texas

<b>Title of Grant</b>	Texas Parent to Parent Health Care Information and Education Program
<b>Name of Grantee</b>	Texas Parent to Parent (TxP2P)
<b>Subcontractor(s)</b>	None.

## Goals and Objectives

- Hire additional staff and upgrade existing infrastructure
- Provide health care information, resources, programs, and other necessary information to parents of CSHCN, parent groups, and service providers/professionals who work with CSHCN on health care services.
- Provide training opportunities to parents of CSHCN and other stakeholders.
- Promote and educate parents, parent groups, and providers/professionals about the philosophy of home and community-based supports.
- Train and provide continuing support to Supporting Parent Volunteers.
- Provide opportunities for peer support and discussions between parents.
- Collaborate with existing Family-to-Family Health Care Information and Education Centers and the Texas Department of State Health Services (TX DSHS).
- Provide opportunities for parents of CSHCN to become parent leaders in health care policymaking and advocacy.
- Assess progress and analyze evaluations on a quarterly basis with staff to identify strategies to improve the project activities, if needed.
- Create a Health Care Education and Training Program within Texas Parent to Parent for parents of CSHCN, parent groups, and service providers and other professionals who work with CSHCN on health care services.

## Activities

- Hire an Outreach & Training Coordinator. Increase hours of Family Support Staff and Resource Specialist by 10 hours/week.
- Create additional computer programs to create personalized resource information for families and obtain additional equipment and office space required.
- Provide general information about and referrals to programs, services, and benefits that can help children stay in their community and progress in their development. Provide individualized information on services for children based on families' personal information (i.e., where they live in Texas, their income information, the age of the child, and the child's type of health care needs and/or disabilities).
- Provide outreach, education, and training opportunities for parents of CSHCN, parent groups, service providers, and other professionals who work with CSHCN on health care services and resources for CSHCN.

- Provide a one-on-one match with a Supporting Parent Volunteer who will supply information, referrals, health care information, and emotional support to new parents or parents new to the special health care need.
- Develop and promote a Transition Program for parents of teens and young adults through written information, articles in the newsletter and on TxP2P's Web site, one-on-one support from a Transition Coordinator, and trainings to be provided in conjunction with other monthly trainings.
- Provide opportunities, including an annual conference, for peer support, discussion, and interaction through the expansion of Internet listservs, the annual statewide parent conference, and matches with Supporting Parent Volunteers. Provide technical assistance and advertising for local parent groups while continuing to identify and provide additional avenues of interaction for parents.
- Maintain current and accurate information on resource lists, Web site resource directory, and newsletter.
- Collaborate with existing Family-to-Family Health Care Information and Education Centers in other states to benefit CSHCN. Continue existing collaborations and pursue additional ones with TX DSHS on best practices and findings from resource dissemination.
- Provide opportunities for parents of CSHCN to become parent leaders in health care policymaking and advocacy.
- Assess progress and analyze evaluations on a quarterly basis with staff to identify strategies to improve the project activities if needed, track number of people contacted through grant activities and number of Parent Leaders. Solicit feedback from parents on the usefulness of the Supporting Parent Volunteer match program, resources, and trainings.

## **Reported Impacts, Outcomes, and Accomplishments**

### ***Impacts:***

- A larger proportion of families and children with special health care needs have access the information and services needed to improve functionality and remain in the community.

### ***Outcomes:***

- Provide support, information, and statewide trainings on health care issues that are effective in connecting families and children with special health care needs to available health care, community services, and supports.

### ***Accomplishments:***

- Texas Parent to Parent provided support and information on resources and services to a total of 1,427 new families, of which 107 were Spanish-speaking only. Parents received a welcome letter, a Texas Resource List, and the latest newsletter in Spanish or English. Families also received resources specific to their geographic area and have access to the online Resource Directory.
- Held 22 booths at conferences and interacted with approximately 2,770 parents and professionals.
- Created and gave 18 presentations about health care issues 100 times to 2,248 parents and professionals.

- Facilitated 3 major parent conferences with an average of 275 families and professionals per year attending (over 800 for the 3 year cycle).
- Provided 23 articles on home and community-based services in 11 newsletters that were mailed to between 1,500 to 2,850 parents and professionals over the three year period.
- Used trainings and advocacy listserv to teach parents how to advocate for their children and their health care services. These trainings promoted home and community-based services.
- Trained a total of 152 new Supporting Parent Volunteers in the importance of Medical Home, home and community-based services, and health care transitioning.

# Virginia

**Title of Grant** The Virginia Integrated Network of Family Support Organizations Center (VA INFO Center)

**Name of Grantee** Medical Home Plus, Inc.

**Subcontractor(s)**

- Graphics design consultant
- Evaluation and strategic planning consultants

**Goals and Objectives**

- Create a statewide Family-to-Family Health Care Information and Education Center (called VAINFO Center) designed to strengthen and expand the capacity to connect CSHCN and their families with services and resources that promote health and well-being.
- Provide leadership (through expansion of the newly forming Integrated Network of Family Support Organizations coalition—VA INFO Coalition) to the Center by linking collaborators and grassroots organizations, and promoting awareness, support, and participation of families.
- Develop a statewide and national presence that supports systems change, providing feedback to Virginia’s stakeholders, CMS, and existing Family-to-Family Health Care Information and Education Centers to improve health care for children.
- Through emotional, informational and advocacy support, increase families’ abilities to coordinate and advocate for the care of their child with special health care needs.

**Activities**

- Gather, create, and disseminate information on resources, services, and training opportunities for families with CYSHCN.
- Promote training and education on home and community services and support for CYSHCN, parent groups, providers, and other stakeholders.
- Create a timely and cost-effective process for sharing information and making referrals that support children and their families in their communities across the Commonwealth (e.g., Medicaid waiver, respite, home health, transportation, etc.) through partnerships.
- Maintain updated information on the Center Web page and share point portal (electronic workspace).
- Coordinate peer-to-peer matches between families for emotional support.
- Partner with family support groups and/or agencies to create new resources for families.
- Provide forums for families in different parts of the State; facilitate peer group discussion.
- Create a process that enables providers and family support organizations to work together to identify needs, develop proposals, and secure funding to address unmet needs of children with disabilities and special health care needs in Virginia.

- Participate in state and local councils, committees, and task forces to help facilitate systems improvements.
- Provide input and feedback to Virginia's stakeholders, CMS, existing Family-to-Family Health Care Information and Education Centers; and status updates to legislators.

## **Reports, Impacts, Outcomes, and Accomplishments**

### ***Impacts:***

- 98% of the 335 callers supported by the Center were highly satisfied with the support they received.

### ***Outcomes:***

- A minimum of 120 families received telephone support from another parent each year and a minimum of 80% of those families will be highly satisfied with the support received by the Center.

### ***Accomplishments:***

- The VA F2F Center supported 751 callers with emotional, informational and advocacy support.
- The Center supported the Strong Roots for Healthy Futures conference, which had approximately 150 participants each year.
- In July 2007, the Center hosted the Strong Roots for Healthy Smiles oral summit, which was attended by fifty family members, health and oral health professionals and policymaker.
- Formed the VA INFO coalition, which had 156 members on the coalition's listserv and an average of 18 members attended bi-monthly coalition face to face meetings.
- Evaluation activities revealed that 98% of those in contact with the Center (through phone, email, trainings, etc.) expressed high satisfaction with the support and information they received.

# Washington

<b>Title of Grant</b>	Family Voices Health Information and Education Center
<b>Name of Grantee</b>	Washington PAVE
<b>Subcontractor(s)</b>	None.

## Goals and Objectives

- Establish a statewide family-directed Family-to-Family Health Information Center in partnership with the Washington Family-to-Family Network (WFFN).
- Survey family needs to identify the information and training to be developed and coordinated through existing Washington State Parent-to-Parent Support Programs Regional Coordinators.
- Expand and improve information, referrals, and linkages to existing community, state, and national programs and agencies providing information on health care and home and community-based services (HCBS).
- Collect data on issues, barriers, and gaps that families identify in accessing public and private health care systems.
- Promote and participate in a collaborative leadership forum with parents, youth, advocacy groups, and stakeholder groups to develop strategies to promote effective, quality and integrated systems of long term care for children with special health care needs.
- Create a clearing house of information that will be supported through an existing partnership with the Washington Family to Family Network.

## Activities

- Establish the Family Advisory Committee, which will meet four times each year in conjunction with the WFFN Partnership Committee.
- Develop a brochure for the Center and disseminate it through a wide variety of current family support and stakeholder groups.
- Develop a self-assessment tool to evaluate the leadership and decision-making skills of the Family Advisory Committee.
- Develop a tool to evaluate the WFFN Partnership with the Center and Family Advisory Committee.
- Survey families in Washington to learn about the training and information they need in order to improve their children's access to health care and HCBS and design trainings based on survey responses.
- Develop and disseminate two one page topic bulletins in Spanish and English.
- Hire at least two Spanish-speaking outreach coordinators.
- Develop and set up guidelines for the listserv. Develop a Web page on the Washington PAVE Web site for the program and informational brochures.
- Assist the Advisory Board in strategic planning.

- Meet with the ARC and the Developmental Disabilities Council to sponsor and support meetings to develop strategies based on the information gathered by the Family Voices Solutions Data System.

## **Reported Impacts, Outcomes, and Accomplishments**

### ***Impacts:***

- The peer support program will enable families of children and youth with special health care needs to have more timely access to information, which will help them improve their decision making capabilities for their children and youth.

### ***Outcomes:***

- Developed a solid functioning structure for providing information and linkages to parent leaders, community/cultural brokers, agencies, programs and individual families with input from our family advisory group and partners.

### ***Accomplishments:***

- Grew a diverse advisory board from six to nine members.
- Community leaders were trained and each of them pledged to continue to serve beyond the grant funding.
- The Advisory Board was instrumental in establishing a process for identifying and supporting consumers and providers' needs for resources.
- Created infrastructure, pooled information regarding special needs services and eligibility requirements, and made it available to consumers via an active listserv and Web site.
- Held five trainings, wrote articles for inclusion in the PAVE Pipeline, online, and for dissemination by other organizations.