
Innovative Strategies for Strengthening Family to Family Health Information And Education Centers

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Prepared by:

**Steve Eiken
Sara Galantowicz
Amanda Stubbs**

**Thomson Medstat
Research and Policy Division
150 Cambridge Park Drive
Cambridge, MA**

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Introduction

Families with children and youth who have special health care needs (CYSHCN) face additional obstacles in navigating an already complex health care delivery system. Children who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions often require additional, and sometimes very specialized, health and related services.¹ Frequently, too, CYSHCN require a variety of services from multiple, diverse funding sources such as private insurance, Medicaid, and the local school district.

In order to best meet all of the needs of their children, families of CYSHCN require an in-depth understanding of the health care system and all of their options. Unfortunately, there is often no clear, family-friendly, easily accessible, and objective source for this information. A family's pediatrician, for example, may not know all the resources available to CYSHCN, or may not have the time to help parents navigate the system. And while some families receive care coordination through private insurance or public sources, care coordinators may also have incomplete information about families' options. As a result, many parents have found the best source of information is their peers - other families of CYSHCN, whose considerable experiences with the health care system has provided them with a wealth of relevant information and knowledge.²

Recognizing this reality, organizations in several communities have harnessed families' expertise to provide training, mentoring, and information and assistance to other families. Since 2002, the U.S. Department of Health and Human Services, through the Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB) and the Centers for Medicare & Medicaid Services (CMS), has awarded grants to establish and enhance Family to Family Health Information and Education Centers (hereafter Family to Family Centers) in 36 states.³ These Centers' mission is to provide information and other supports both to family members and to professionals who serve CYSHCN. Recently authorized Congressional grants will establish Family to Family Centers in all 50 states and the District of Columbia by 2009.⁴

¹ HRSA. "HRSA Awards Funds to Education Centers Run by Families of Children With Special Health Care Needs" July 19, 2002.

² Wells, N., Krauss, M.W., Anderson, B., Gulley, S., Leiter, V., O'Neil, M., Martin, L., and Cooper, J. *What Do Families Say About Health Care for Children with Special Health Care Needs? Your Voice Counts! The Family Partners Project Report to Families* Boston, MA: Family Voices at the Federation for Children with Special Health Care Needs. April 2000.

³ Together MCHB and CMS have awarded \$7 million in grants to organizations in 36 states. CMS grants were awarded from 2003 to 2005 and are part of the Real Choice Systems Change Grants program. HRSA grants in 2002 and 2006 are through the Children with Special Health Care Needs Program, which is part of the Maternal and Child Health Grants authorized by Title V of the Social Security Act. In addition, MCHB will award six more grants in 2006.

⁴ Section 6064 of the Deficit Reduction Act of 2005

In fulfilling their mission to inform and support families and providers, the Family to Family Centers share several core activities and goals, including:

- Providing information and referral to help link families and providers with services
- Developing and disseminating accessible materials;
- Educating families and providers about services and benefits;
- Enhancing the capabilities of health care professionals to care for CYSHCN;
- Creating partnerships with other organizations to expand the information network;
- Helping families and providers prepare for major disasters, as well as minor life transitions; and
- Maintaining sustainability to ensure continuity in service delivery and information support.

There are, however, many challenges faced by Family to Family Centers in providing their valuable support and meeting the goals outlined above, including inadequate staffing and resources, a broad and diverse client base, and lack of parent participation and information about available programs information.⁵ The working relationship between MCHB and CMS has resulted in a network of Centers across the country that share strategies and materials for assisting CYSHCN, their families, providers, and communities. To facilitate this information-sharing, this document provides specific information on selected innovative strategies developed by individual Family to Family Centers to address some of these challenges and enhance their core activities, and is intended to be a resource to other organizations performing similar activities seeking to do the same.

These examples were gleaned from interviews with people who work regularly with the Family to Family Centers, including staff from CMS, HRSA, and Family Voices, Inc., the national technical assistance provider to these grantees, as well as conversations with the grantees themselves. Based on their guidance, Medstat explored innovative strategies and promising practices in five broad areas directly related to grantees' mission and key challenges. These areas are:

- Developing partnerships to leverage limited resources and increase organization capacity;
- Enhancing communication and outreach with parents;
- Developing culturally appropriate strategies to serve a diverse audience;
- Helping CYSHCN and their families prepare for the transition to adulthood; and
- Ensuring organization sustainability by accessing multiple funding sources.

This paper is organized along the themes identified above. Following a brief overview of the Family to Family Centers are examples of grantees' implemented strategies to strengthen their Center, grouped by theme. Additional information and background on these practices was also obtained by reviewing grantees' Web sites and their annual grant reports. After each example, contact information is included so readers may easily learn more about particular practices.

⁵ For an expanded discussion of the activities of Family to Family Centers, and the challenges they face, see "Activities and Accomplishments of the Family to Family Health Care Information and Education Center Grantees", by Angela Greene, Edith Walsh, Janet O'Keefe, and Elizabeth Koetse; RTI International, April 2006

Overview of Family to Family Health Information and Education Centers

The goal of Family to Family Centers is to provide information and assistance to families of CYSHCN, and the professionals who work with them, to enhance families' role in managing their children's health care and other services. The Centers provide education and training opportunities for families with CYSHCN and providers, and develop and disseminate information on health care delivery, health care financing, and home and community-based services to families and providers. In addition to these duties, the 29 CMS grantees must promote a philosophy of individual and family-directed supports. The eight MCHB grantees must also promote family-centered care, family/professional partnerships, and services that are appropriate to their clients' varied cultural backgrounds.

The health care information provided by these Centers often relates to six core areas of information and education. MCHB identified these core areas based on lessons learned from years of working with families, youth with special health care needs and CYSHCN health systems. MCHB grantees are required to provide information to increase access and utilization of these core areas:

- Coordinated care within a medical home, including a provider who knows about and coordinates medical care for the child;
- Adequate private and public health insurance;
- Early and continuous screening and intervention services;
- An organized and easily accessible community system of services for CYSHCN;
- Opportunities for families to be partners in decision making at all levels; and
- Services for youth necessary to make the transition to adulthood.⁶

Because addressing these areas is consistent with the Family to Family Center philosophy, many CMS grantees also provide information and support on these topics.

⁶ These six areas are also the core outcomes for an integrated community system of services, as promoted by HRSA and MCHB.

Developing Partnerships to Increase Organizational Capacity and Outreach

The amount and complexity of the information Family to Family Centers strive to share with families and professionals requires them to form linkages with other organizations to foster well-developed information and outreach networks. Such partnerships allow the Centers to leverage existing resources efficiently, and reduce duplication with other organizations that also provide information and assistance. Indeed, given the limited financial and staffing resources most Family to Family Centers face, these partnerships are essential. This section describes some of the Centers' more innovative and effective partnerships, which have enabled these organizations to expand their services and enhance the lives of CYSHCN and their families. The examples are organized by the type of partnerships, and include:

- Partnering with University Programs for Health Professionals;
- Partnering with State Agencies;
- Partnering with a State Bureau of Emergency Medical Services;
- Partnering with Community Physicians;
- Partnering with Hospitals; and
- Partnering with Other Community Organizations.

Partnering with University Programs for Health Professionals

Families with CSCHN interact with a large and diverse group of health professionals who provide care for their children. Of these, a child's physician is often the primary focal point for assuring that CYSHCN receives the services they require. In recognition of physicians' lynchpin role in coordinating services, many Family to Family Centers have partnerships with medical schools to give pediatric medical students, interns, or residents a family perspective on living with a CSCHN early in their medical careers, to help them better understand the issues families face so they can deliver care in a family-centered manner.⁷

In addition to pediatricians, other providers, including dentists, nurses and specialists, can also be essential players in the continuum of care provided to CYSHCN, and some Centers reach out to them as well. Arizona's *Raising Special Kids* and *Parent to Parent of Vermont* are examples of two family-based organizations partnering with medical schools to provide pediatric medical students and residents with a family perspective on living with a CYSHCN, who also share this perspective with other health professionals, such as nurses, dental students, special education workers, and speech, physical, and occupational therapists.

Parent to Parent of Vermont and the University of Vermont College of Medicine began a partnership over 20 years ago when the school asked *Parent to Parent of Vermont* to train physicians on treating people with disabilities. Pediatricians identified training as a need after

⁷ A total of 28 states have such "family faculty" programs funded in part by grants from the Leadership Education in Neurodevelopmental and Related Disabilities program, managed by HRSA's Maternal and Child Health Bureau. The MCHB provides funds to medical schools through the Special Projects of Regional and National Significance portion of the Title V Block Grant to set-up these programs. More information about this program, including information on how to apply for grants, can be found at http://www.aucd.org/aucd_lend.htm.

several people with disabilities were in a car accident and their injuries went undiagnosed in the emergency room. Pediatricians contacted medical school leadership and identified *Parent to Parent of Vermont* as a resource because of the organization's previous work with families. In later years, training was expanded to include presentations to nursing, special education, and speech, physical, and occupational therapy classes.⁸ In addition, *Parent to Parent of Vermont* also organizes parent panels for its annual Partners in Care conference, attended by social services professionals, policymakers, educators, and health care providers from around the state. These panels allow conference participants to hear how parents experience family-centered care, family/professional partnerships and the health care system in general.

Arizona's *Raising Special Kids* has resident programs set-up with nine hospitals, one nursing school, and a dental school. These partnerships began when the organization contacted Residency Program Coordinators at the hospitals, with the assistance of the Department of Health Services which funds the residency program. Partnering with *Raising Special Kids* allowed the Coordinators to expand community rotation options in the residency program, by linking residents with parents of CYSHCN, and provided opportunities for dental, medical, and nursing students to develop skills for working with this population.

Contact Information:

❖ ***Parent to Parent Vermont***

Hilary Melton
hilary.melton@partoparvt.org
(802) 764-5290
www.partoparvt.org

❖ ***Raising Special Kids***

Wendy Benz
wendyb@raisingspecialkids.org
(602) 242-4366
www.raisingspecialkids.org

Partnering with State Agencies

Just as families with CYSHCN interface with a range of providers, they must frequently negotiate a number of state programs as well. Their children may be receiving services from Medicaid, including the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program, Title V, public health agencies, and other state programs. Coordination between Family to Family Centers and the state agencies whose programs serve CYSHCN can reduce the information burden for families and increase outreach and efficiencies for state staff.

Family Voices of Colorado was able to foster such coordination by building upon longstanding relationships between parent leaders and the agencies and programs that supported their children. The staff members of *Family Voices* have children with special needs who utilize or have

⁸ Information about *Parent to Parent of Vermont's* family faculty program, including a booklet of information for downloading, can be found at <http://www.partoparvt.org/ffi.html>.

utilized Medicaid, EPSDT, and Title V programs in Colorado, as well as the mental health, developmental disability, special education, vocational rehabilitation and other health and social services systems. This has provided them with an understanding of and connection to these multiple state systems. In addition, staff served on several advisory boards and work groups, and participated in conferences, which helped bring *Family Voices* to the attention of the Colorado's service systems. These targeted efforts to work with agencies on well-defined goals gave *Family Voices* the ability to impact service delivery, funding support, and overall awareness about CYSHCN and their families.

In collaboration with Title V CYSHCN program staff, the Center delivers a series of training sessions for professionals and families drawn from 14 regions of the state. The partnership allows the participating organizations to collaborate efficiently on the trainings and comprehensively address the needs of participants, who include both family members and professionals, such as advocates, special education staff, early intervention staff, and case managers from the mental health and developmental disability service systems. *Family Voices of Colorado* identifies training topics, arranges for expert speakers from other organizations where appropriate, and develops the training materials. State employees with outreach responsibilities for the state Title V CYSHCN program⁹ and for Medicaid's EPSDT program join *Family Voices of Colorado* in planning and conducting some of the training sessions. Title V family coordinators and other staff is also encouraged to make taped copies of the training available to families and to offer themselves as additional sources of information.

To take maximum advantage of the partnership, *Family Voices of Colorado* combines several training sessions, so staff visit each local office only once per year. The training covers a broad array of topics relevant to families with CYSHCN. Topics have included private and public funding sources, the medical home, coding and billing, encouraging family advocacy, self-determination, the mental health system, and the transition to adulthood.

The Parents' Place of Maryland has developed a similarly strong partnership with the state Department of Health and Mental Hygiene, which administers both the Medicaid program and the Title V CYSHCN program. This relationship began several years ago with informal meetings to provide information about families' experiences and to explore the Department's need for assistance and information, as part of the Department's efforts to seek input from stakeholders during an organizational redesign. This informal contact resulted initially in *The Parents' Place* participation in Departmental advisory committee meetings, including the Special Needs Children Advisory Council. Based on the organization's thorough and significant work on these committees, the Department and *The Parents' Place* pursued more formal options for working together, including sharing staff and contracting arrangements.

In discussing the key to its successful partnership with the state, staff at *The Parents' Place* emphasized the collaborative nature of the organization's advocacy. Rather than presenting issues and concerns to state agency staff in an adversarial manner, they have focused on

⁹ Each state and territory has a program to support children and youth with special health care needs, funded in part by block grants authorized by Title V of the Social Security Act. The Maternal and Child Health Bureau within HRSA administers the grants, which fund infrastructure development, information and assistance, and direct services. More information CYSHCN program is available at <http://mchb.hrsa.gov/programs/default.htm>.

developing partnerships with them to address problems their consumers and constituents are facing. *Parents' Place* staff also emphasized that a considerable amount of time was needed to build trust with government agencies because of concerns about the long-term viability of the Center, as well as the fear that *The Parents' Place* staff would be critical of the State in the press.

This formal partnership has benefited both the Center and the State in several ways. To enhance the state's resources and increase outreach to families with CYSHCN, *The Parents' Place* provided the Medicaid agency with one of their employees, who worked onsite at the agency one day a week to assist with special projects related to CYSHCN. This provided the agency with free advice and feedback to improve services and programs. *The Parents' Place* employee also served on the Medicaid Advisory Committee and on the Special Needs Children Advisory Council. In addition, she played an important role in designing new brochures to inform families about Medicaid services for CYSHCN. *The Parents' Place* funds this position through health related grants from the Title V CYSHCN program and private foundations.

The Parents' Place's relationship with the Title V CYSHCN program grew after a CYSHCN redesign study in the late 1990s recommended the program solicit more input from parents. Today, the Title V program contracts with *The Parents' Place* for several tasks, including a project to develop an online database of resources for CYSHCN and an effort to educate physicians regarding the importance of a medical home.

Contact Information:

❖ *Family Voices of Colorado*

Lorri Park
lorri@familyvoices.co.org
(303) 447-8447
www.familyvoicesco.org

❖ *Parents' Place of Maryland*

Kim McKay
Kim@ppmd.org
(410) 768-9100
www.ppmd.org

Partnering with a State Bureau of Emergency Medical Services

While much of the care required by CYSHCN is routine and on-going, families also need information and assistance in preparing for and addressing emergency situations. These can include emergency medical crises, as well as natural disasters and other emergencies on a larger scale. Helping families prepare for emergencies is another key component of Family to Family Centers' mission and one that can be strengthened through partnership with relevant state agencies.

The *Florida Institute for Family Involvement (FIFI)* is a leader in this area through its partnership with the Bureau of Emergency Medical Services (EMS) in the Florida Department of Health. This partnership grew out of the relationship established when *FIFI's* executive director was serving as a consultant to the Emergency Medical Services for Children (EMS-C) program National Resource Center.¹⁰ Staff from the state's EMS-C recognized the benefit of having family input and *FIFI's* executive director now serves on state's EMS-C advisory committee. To assist families with emergency planning, FIFI had developed a two-page form for families to record information about their child, which they can keep with them if they need to evacuate during an emergency. Recognizing the value of such a tool, the Bureau of EMS has printed and distributed over 30,000 of these forms, using its network to expand outreach for FIFI's materials. In addition, *FIFI* approached the state Bioterrorism Work Group and offered to serve as a representative of families of CYSHCN. This resulted in an opportunity for *FIFI* to provide input to the state's strategic plan for disasters and terrorism, to help ensure that efforts are family-centered, culturally appropriate, and applicable to CYSHCN. FIFI has also conducted several emergency preparedness and response training sessions across the state for families, family-run organizations, and employers.¹¹

Contact Information:

❖ ***Florida Institute for Family Involvement***

healthhelp@fifionline.org

1-800-926-3514

www.fifionline.org

Partnering with Community Physicians

As noted above, physicians play an integral role in providing and coordinating care for CYSHCN. Partnerships with physicians are important not only when they receive their training, but also after they begin providing care in the community. Through community based physicians, Family to Family Centers can expand outreach to families with CYSHCN beyond the limits of their own staffs.

The Parents' Place of Maryland has been particularly effective in working with the medical community to improve outreach to families, through a variety of initiatives with community-based pediatricians. The pediatrician outreach was informed by two strong partnerships. First, *The Parents' Place* staff frequently meets with leadership from four medical centers that are important providers for CYSHCN. During one meeting, *The Parents' Place* observed several

¹⁰ Each state and territory has a program to enhance emergency medical services for children (EMS-C), funded in part by grants authorized by the Public Health Act. The Maternal and Child Health Bureau within HRSA administers the grants in partnership with the U.S. Department of Transportation, National Highway Traffic Safety Administration. More information on the EMS-C program is available at <http://mchb.hrsa.gov/programs/emsc/>.

¹¹ FIFI also has developed an emergency preparedness guide for families with CYSHCN, which is available online at <http://www.fifionline.org/images/PDF%20Files/PDF%2010-13-05/Ready.pdf>. Recently, 7000 copies of the guide were distributed by the Governor's office at the statewide disability conference. The emergency preparedness guide was not a result of the partnership with the EMS, but instead was jointly supported by the Family to Family Grant and a Statewide Family Network Grant from the Substance Abuse and Mental Health Services Administration (SAMHSA).

families in a clinic waiting room and asked to put brochures there. Second, *The Parents' Place* conducted focus groups with the state chapter of the American Academy of Pediatrics (AAP). These focus groups revealed that that pediatricians would like a resource to refer families for support and for information on health related services. Center staff first made contact with leaders in both the four medical centers and the local AAP chapter at a variety of meetings regarding CYSHCN, including state government advisory panels for Medicaid and the Title V CYSHCN program described above.

Specific outreach activities include a project to place informational brochures in many pediatric clinic waiting rooms and efforts to encourage referrals from physicians and clinic office staff. *The Parents' Place* first collected contact information for the pediatricians by asking families to name the top five pediatric clinics in their area. They then sent letters to each clinic describing the organization and resources available for families there. *The Parents' Place* staff and volunteers followed up with a phone call and then an in-person visit. When visiting in-person, people brought a little gift for the physician and staff, in addition to the brochures, as a token of appreciation.

Contact Information:

❖ *Parents' Place of Maryland* (provided above)

Partnering with Hospitals

While community-based staff may be the primary players in providing care to CYSHCN, these children's conditions often result in use of inpatient services, as well as clinics and other inpatient services located within hospitals. Their families need information not only on hospital policies and services, but options and resources available after discharge. Partnerships with hospitals enable Family to Family Centers to provide outreach and education around this crucial component of the health care delivery systems for CYSHCN.

In order to reach this population, New Jersey's *Family to Family Center at the Statewide Parent Advocacy Network (SPAN)* has formed a partnership with three hospitals in the state that serve many CYSHCN and has established a Community Health Resource Center on-site at each. The three hospitals, UMDNJ Child Behavioral Health Center in Newark, Morristown Memorial Hospital, and Capital Health Systems in Trenton, are among 12 organizations statewide that host *SPAN* staff and volunteers at satellite offices. The first hospital partnership, with the Child Behavioral Health Center, grew out the relationship between representatives from both organizations who sat on both the Essex County Child Welfare Human Services Committee and Child Welfare Planning Council.

Based on this experience, *SPAN* used its existing network of relationships to approach two additional hospitals to pursue further collaboration in meeting the needs of families and their CYSHCN. In one hospital, *SPAN* staff had connections with a developmental pediatrician in their Children's program who had referred patients to the Center, and used this relationship to look at on-site opportunities. The partnership with a third hospital began after the March of Dimes contacted *SPAN* about supporting families with children in the neonatal intensive care

unit (NICU). Currently, *SPAN* is working with the NICU staff to provide family-to-family emotional support and information and assistance to families with newborns in the NICU. Based on this successful collaboration, two more hospitals with NICUs have approached *SPAN* to establish a similar relationship.

In order to reach out to more parents and families in the hospitals and other settings, *SPAN* trains one or more staff members or volunteers; generally parents of CYSHCN called “Resource Parents”, to staff each Community Health Resource Center. The *SPAN* staff and resource parents represent multiple languages, diverse cultures, and a range of special needs. Resource parents provide access to written materials, conduct workshops, and offer technical assistance and support as families work with the health system. Similar training and technical assistance is also made available directly to hospital staff. New Jersey’s Title V CYSHCN program funds part of the resource parent training.

This partnership has not only expanded *SPAN*’s organizational outreach, but also made more efficient use of hospital resources. By combining the resource center with the hospital’s family resource room in two hospitals, *SPAN* has helped these facilities make better use of previously underutilized space. *SPAN* uses the resource centers to meet with families, to provide them with access to written materials, and to conduct family workshops. *SPAN*’s letter of agreement with each hospital also includes a provision to allow resource parents to attend staff meetings. The meetings provide an opportunity for staff to hear family perspectives and for the resource parents to learn more about hospital policies, services available through the hospital, and how to access them effectively. In addition, these meetings allow hospital staff and resource parents to develop and strengthen the personal relationships that are essential in successful partnerships. *SPAN* has also strengthened partnership, collaboration and trust between the organizations by having a developmental pediatrician from one of the partner hospitals on their Advisory Committee.

Contact Information:

❖ *New Jersey Family to Family Center at the Statewide Parent Advocacy Network (SPAN)*

Diana Autin

diana.autin@spannj.org

(973) 642-8100, ext. 105

1-800-654-SPAN ext. 105 (toll free in New Jersey only)

www.spannj.org

Partnering with Other Community Organizations

The support system for CYSHCN and their families includes many players besides hospitals and physicians. Bringing them into a Family to Family Center’s network allows the Center to provide families and providers the most comprehensive information and support. It also allows the Centers to fill gaps in their own information resources, and avoid duplication with existing outreach efforts.

As noted above, New Jersey’s *SPAN* has established local satellite offices in a variety of community settings besides hospitals, including the Association for Special Children and

Families in Sussex County, the Bloomfield Municipal Building in Essex County, El Club de Padres of Catholic Family and Community Services in Paterson, Passaic County, schools, churches, and various disability-specific organizations. These Community Health Resource Centers were established via outreach by *SPAN* staff seeking to identify locations to conduct workshops for families. When a community-based site hosts a workshop and when staff there indicate an interest in greater collaboration, *SPAN* works with the site to develop its capacity to become a resource center, which then allows *SPAN* staff and volunteers to be on-site where families receive services. *SPAN* has developed a Community Resource Center collaboration agreement that clearly identifies the responsibilities of each partner. *SPAN* provides resources for each Center, including fact sheets, brochures, information packets, manuals, videotapes, and CDs for use by families, advocates, and professionals. *SPAN* also conducts a comprehensive series of workshops at each Resource Center at least every other year to keep a trained cadre of volunteers up-to-date. In addition, *SPAN* provides a small grant of \$500/year to each Community Resource Center to be used to support their efforts. Centers may use these funds for postage, refreshments for meetings or trainings, materials, or other purposes that serve families.

Parent to Parent of Vermont is another Family to Family Center that has partnered with local community-based organizations to establish local satellite offices in order to improve information outreach. The Center took a deliberate approach to expanding its network and identified potential partners by 1) identifying family support organizations that have offices in each county, and 2) asking families in these communities which organizations were the most family-friendly and provided services that complimented the Family to Family Center. The organization then selected local communities based on where the unmet need was considered greatest. Staff used their existing relationships with these organizations to start conversations about potential collaboration. Outreach to potential partners was facilitated by the small size of the state, and the already close relationships between many social services agencies.

Lacking resources to hire full-time staff in the satellite offices, *Parent-to-Parent of Vermont* developed an innovative approach to address this challenge. Staff in the satellite offices is employed part time by *Parent-to-Parent of Vermont* and part time by the host organization. This joint employment allows both organizations access to a dedicated employee and provides opportunities for cross programming, as one person provides information and support available from multiple programs. This highly effective partnership has enabled *Parent to Parent of Vermont* and the partner organizations to reach more families using limited resources.

Parent-to-Parent of Vermont's community partners include a local early intervention program, a pediatrician's office based at a medical center, and a multi-service child development center. From these satellite offices, as well as from a fourth home-based office, the jointly-employed staff conduct outreach to local physicians and service agencies, receive local calls for information and assistance, and provide training for nearby parents who want to become volunteer mentors or support group leaders. The investment in this partnership is paying off; in each community where *Parent to Parent Vermont* has placed local staff, the number of calls for information and assistance increased by 28% or more.

In Wisconsin, *Family Voices of Wisconsin* and other information and assistance agencies were interested in reducing potential duplication of efforts and identifying gaps in their existing outreach and service efforts. Seeking a systemic approach to improve coordination, *Family*

Voices of Wisconsin convened a series of meetings with 22 organizations that provide information, assistance, and/or advocacy to people with disabilities and families with CYSHCN or disabilities. The center identified the organizations in partnership with the state's University Center for Excellence in Developmental Disabilities,¹² the state's Protection and Advocacy agency,¹³ and the Title V CYSHCN program. The process was facilitated by the fact that *Family Voices of Wisconsin's* project director also works for the state's University Center for Excellence in Developmental Disabilities and had developed relationships with key staff at the Title V CYSHCN program and at the Protection and Advocacy agency.

The result of these meetings was expanded knowledge, coordination and outreach for all the providers involved. Participating organizations learned more about each other's strengths and, in some cases, learned about new resources for their staff and consumers. The group also developed a statement of purpose that identified areas of common interest and potential collaboration related to outreach, training, database coordination, and identification of unmet needs. To formally capture the results of this new partnership, *Family Voices of Wisconsin* developed a web-based annotated list of agencies and a chart that presents information regarding each organizations mission, service population, services provided, geographic area, capacity, and gaps in its services.¹⁴

Despite its limited resources as a relatively small agency, *Family Voices of Wisconsin* was able to foster this network of community partnerships because it began with close connections with the multiple partner organizations. Working on a local level, smaller organizations who are just starting out and who lack a well-developed network may be able to increase communication and coordination by focusing on specific Information, Assistance & Advocacy agencies.

Contact Information:

- ❖ ***Family Voices of Wisconsin***
Liz Hecht
liz@fvofwi.org
608- 239-1364

www.wfv.org/fv
- ❖ ***SPAN*** (provided above)
- ❖ ***Parent to Parent Vermont*** (provided above)

¹² Each state and territory has a University Center for Excellence in Developmental Disabilities Education, Research, and Service to train professionals, provide technical assistance, and conduct research. The centers are funded in part by grants from the Department of Health and Human Services, Administration on Developmental Disabilities (ADD). More information on the centers is available at <http://www.acf.hhs.gov/programs/add/states/ucedds.html>.

¹³ Each state and territory designates a Protection and Advocacy agency that provides information, assistance, and advocacy for people with disabilities. Protection and Advocacy agencies are funded in part by federal grants from HRSA, SAMHSA, ADD, the Social Security Administration, and the Department of Education's Office of Special Education and Rehabilitative Services. More information on the agencies is available at http://www.napas.org/P&A_Enabling_Laws/P&A%20CAP%20history%20home.htm

¹⁴ This chart and links to information, assistance, and/or advocacy organizations are available on the Internet at <http://www.wfv.org/fv/ir/>

Enhancing Communication with Families

Reaching out to families with CYSHCN is one of the most fundamental aims of all Family to Family Centers. The information and expertise possessed by these Centers is only useful if it is put into hands of the families who can truly benefit from the experience and knowledge of others. Reaching out effectively to a geographically and culturally-diverse parent community can be challenging, however. Constrained by limited staffing and resources, Family to Family Centers seek to use these resources efficiently and take maximum advantage of the many family volunteers who support these organizations. This section highlights some Family to Family Centers' innovative use of select tools to communicate with families.

Across the country, Family to Family Centers provide families of CYSHCN information about the health care system in several ways, including:

- Call-in lines answered by trained parents for families and professionals seeking information and assistance;
- Electronic newsletters providing updates on available training and local system changes;
- Websites comprising information on available services, including links to other organizations' resources; and
- In-person training for families and professionals who work with families.

In addition, we identified several promising practices within selected states for enhancing communication and outreach with families, including:

- Conducting a needs assessment to better target services;
- Creating an online curriculum for families to train themselves;
- Conducting parent leadership trainings to expand the volunteer skill-base;
- Establishing local boards to gather input and disseminate information; and
- Using videoconference to reach families in remote areas.

Specific examples of each of these activities are presented below.

Using Needs Assessments to Target Services

Making sure that the right information reaches the right people is one key way to maximize volunteer and staff time. Family to Family Centers, however, often face a dispersed and unknown constituency, who may not even know what information and supports they are seeking. Efforts to focus outreach can be hampered by a lack of information about the target population.

Stone Soup Group, a Family to Family Center in Alaska, addressed this problem by surveying both families and providers/agencies to determine how they could best serve both groups. In order to reach a large, unknown audience while working within patient confidentiality requirements, *Stone Soup Group* disseminated the survey through public health nurses, rural health clinics, and providers who serve children with developmental disabilities. Providers distributed the survey, but left it to the consumer to contact *Stone Soup Group*. Over the course of the project, the center distributed 1,000 paper surveys through 25 agencies, and received 180

responses. Approximately 50 additional surveys were e-mailed to families who were already in contact with the organization. An Internet survey service administered the survey and tabulated the data for a minimal monthly fee. Almost all the e-mailed surveys were returned.

Surveying families benefited the organization in two ways. Not only did the survey identify families who needed the organization's training and services, it was also a tool to recruit volunteers for parent-to-parent mentorship and other supports. About one-third of the respondents, 80 people, expressed interest in volunteering, and Stone Soup Group is now training some of these people to be parent mentors. And, based on the success of the electronic survey, *Stone Soup Group* now sends this tool to assess the needs of new families referred to the organization, allowing them to obtain valuable information at minimal cost.

Contact Information:

❖ ***Stone Soup Group***

Katy Parish

katyp@stonesoupgroup.org

(907) 561-3701

www.stonesoupgroup.org/f2f/

Creating Online Curricula for Independent Training

Sometimes the best way to communicate with families is to provide them the tools and opportunity to access the information they need themselves, and on their own timetable. Online materials give users the flexibility to view information when and as often as needed. Developing specific curricula helps parents by winnowing the considerable amount of online materials to identify relevant and accurate information.

To do just this, *Raising Special Kids* in Arizona is developing a comprehensive training curriculum on health care delivery systems that will be available online for families to access on their own. These materials will comprise information on the major private and public funding sources for health and health-related services in the state for CYSHCN. *Raising Special Kids* is using a standard format for information across programs to ensure families receive the same types of information for each program, including the program's purpose, the number of people served, eligibility criteria, available services, the enrollment process, and premiums or other costs families must pay. The Arizona Department of Health Services' Office for Children with Special Health Care Needs will display the curriculum on its website once it implements a department-wide learning management system. These same training materials will also be available during health care system training sessions led by *Raising Special Kids*.

In addition to offering families convenient and consistent materials, the website will also customize the information presented. After users enter basic demographic information, the site will direct families to information on programs/services that best fit their needs and financial status. The learning management system will conduct pre- and post-testing for the materials to document whether the training is effective and to identify necessary changes. The Office for CYSHCN will maintain and update the training curriculum and provide Spanish translation once it is online.

Online training can also be a valuable means for reaching and educating parent volunteers. *Parent to Parent of New York State* developed an interactive, online training course to train support parents in their parent to parent matching program. To develop the online training, *Parent to Parent of New York State* staff developed training objectives and then wrote content that reflected those objectives. One employee with a basic knowledge of Internet programming developed the software, searching the Internet as appropriate for existing tools to present information in a variety of ways. Once the software was developed, *Parent to Parent of New York State* established two levels of review. The first reviewers were staff, board members, and an outside expert who lead training for another organization. After their comments were incorporated, experienced support parents provided a second review. Their suggestions were included before new support parents used the training.¹⁵

Trainees' primary contact throughout the training is their regional coordinator, a staff person who supports mentor parents on an ongoing basis. Regional coordinators introduce trainees to the online training by sending them an introductory letter and a password that allows them to view the material. When users complete each section, the system asks a series of questions to test whether users understand the information. The system then sends an update to the regional coordinator that includes answers to the questions. The coordinator reviews the answers and provides technical assistance when necessary

Presenting the training online, rather than in-person, provides a more convenient way for parents to receive training and become mentors. The system tracks the user's progress, so parents can stop at any time and return at the same place in the training. Parents can fit small blocks of time for training over several days, rather than arranging for child care - and other supports their children may need - for a training session. In addition, the training course builds on other resources available for the parent mentor program. For example, *Parent to Parent of New York State* had already developed a support parent manual, which is distributed in hard copy. The online training session refers to the manual, so users review the training materials and manual simultaneously. Support parents also use the manual on an on-going basis to answer questions that arise as they work with families.

Contact Information:

❖ ***Parent to Parent of New York State***

Rosemary Randazzo

rr815@aol.com

(631) 493-1716

www.parenttoparentnys.org

❖ ***Raising Special Kids*** (provided above)

¹⁵ These training materials can be viewed online at <http://www.parenttoparentnys.org/onlinetrainingcenter.htm>.

Expanding Volunteers Skills through Parent Leadership Training

Parent volunteers are an essential resource for all Family to Family Centers. The organizations' peer education model relies on having dedicated and well-trained families members who can connect with other families of CYSHCN. Volunteers are yet another way small Centers can make the most of their limited resources, but investments in finding, developing, and supporting effective volunteers are necessary for a successful peer organization.

In order to ensure an adequate supply of trained and competent volunteers, *The Parents Place of Maryland* developed and conducted a seven-part leadership training series to recruit and train new parent leaders.¹⁶ Leaders were selected through an application process to target training to a diverse group of potential leaders. Up to 20 volunteer family members of CYSHCN learned about *The Parents Place's* approach to building partnerships, understanding the health care system, and reaching out to the local health community. The trainees meet for one full-day each month from October 2005 to May 2006, using the curriculum *The Parents Place* developed. Speakers for the sessions include physicians, politicians, health insurance executives, parents, and representatives from local, state, and federal agencies. Participants are assigned mentors that assist them with their monthly homework, and help them complete a year long project. These newly trained leaders are to play a pivotal role in the center's outreach by providing system level advocacy for their local health community and helping continue state-level advocacy with state agencies and major providers after the Family to Family grant ends.

Contact Information:

- ❖ *Parents' Place of Maryland* (provided above)

Establishing Local Boards to Gather Input and Disseminate Information

Family to Family Centers strive to be responsive to the information and support needs of all their constituents. This can be challenging, especially in large states where reaching out to geographically-dispersed families is difficult. For successful, responsive outreach, Centers need not only mechanisms for disseminating information, but avenues for channeling constituent questions and concerns back to the organization.

In the rural state of Montana, *Parents, Let's Unite for Kids (PLUK)* established Regional Associate Boards across the state to achieve both these goals. The boards both:

- provide a forum for families in rural areas to articulate their needs and concerns, and
- disseminate information to families and professionals in these areas.

To establish each board, *PLUK* sent a letter to everyone on its mailing list in the region. The letters explained the Associate Board concept, with an emphasis on communication rather than fundraising, and asked for people interested in forming such a board. *PLUK* staff then invited interested family members to an inaugural meeting, where the boards were established and officers elected. The Associate Board members continue with monthly meetings. *PLUK*

¹⁶ Copies of the leadership training materials are currently available directly from *Parent's Place of Maryland*, and will eventually be posted on the Family to Family portal.

actually established the boards before it received the Family to Family grant, when it focused on informing parents regarding educational services. After receiving the Family to Family Grant, *PLUK* broadened the boards' focus and membership to include health concerns

PLUK currently has 17 Associate Boards, including a board on each of Montana's seven American Indian reservations. Each Associate Board elects one person to serve on *PLUK*'s Board of Directors. These board members usually participate in *PLUK* board meetings via telephone. The boards also recruit volunteers to assist *PLUK*'s field staff -16 individuals scattered across the state who provide education and health-related information and assistance. In addition, several boards hold fundraising events.

Contact Information:

❖ *Parents, Let's Unite for Kids (PLUK)*

Dennis Moore

dmoore@pluk.org

(406) 255-0540

www.pluk.org

Using Videoconference to Reach Families in Remote Areas

Technology can be another innovative way to reach out to families in rural and remote areas, when local staff and volunteers are not available. Both *PLUK* and *Family Voices of Tennessee*, a program of the Tennessee Disability Coalition, have used videoconferencing for several training sessions in order to increase rural families' access to training. While these two Centers took different approaches to securing a videoconference network, both found it a convenient way to connect people to high quality speakers.

To secure videoconferencing access for families and volunteers, *PLUK* purchased network access from a local technology company that had dozens of sites in schools across Montana. This company charges the center a relatively small fee for the service, based on the number of sites used and amount of time used. In Tennessee, *Family Voices of Tennessee* has been able to go one step further and obtain complimentary network access, by using a network at Tennessee State University. Equipment expenses are paid for by a grant from the school. In return for the opportunity to join the network, *Family Voices of Tennessee* provided materials for the University network on issues related to the Americans with Disabilities Act. Five sites outside of Nashville had access to the training: three sites affiliated with the university's network and two regional Tennessee Department of Health offices.

Family Voices of Tennessee has made an effective use of videoconferencing a priority and worked hard to capitalize on this technology. Prior to the arrangement with Tennessee State University, the center used the Department of Transportation's network, which connects nine district offices. Access was secured by writing a letter directly to the Commissioner. As a result, the Department paid the cost for use of the equipment and connections for several video conferences on health care related issues. *Family Voices of Tennessee* further leverages its videoconferencing capabilities to reach rural communities by using a train-the-trainer approach for selected topics. Under this model, volunteers and family members who attend the videoconference sessions share the information presented with others in their area. *Family*

Voices of Tennessee videoconferences often have three or fewer presenters and they always focus on changes in TennCare, the state's Medicaid managed care program, followed by information on a specific program for a special subpopulation. The TennCare updates are very popular, and provide *Family Voices of Tennessee* significant publicity.

Contact Information:

- ❖ ***Family Voices of Tennessee***
Dara Howe
familyvoices@tndisability.org
(615) 383-9442 ext. 13
www.tndisability.org

Developing Culturally Appropriate Strategies to Serve a Diverse Audience

Families with CYSCHN reflect the full range of our nation's ethnic and linguistic diversity. In order to successfully meet all their needs, Family to Family Centers must develop culturally appropriate ways to communicate with this diverse audience. In our conversations with several Centers, they emphasized the importance of developing cultural competence in order to effectively provide information and assistance to all families with CYSCHN. Cultural competence is a set of attitudes, skills, behaviors, and policies that allow organizations to work successfully in cross-cultural situations. It requires staff to have a certain level of awareness and acceptance of cultural differences; knowledge of a patient's culture; and the ability to adapt skills to effectively work with families from diverse populations¹⁷. Often, families with similar cultural, ethnic and linguistic backgrounds are the most helpful in impacting the health behaviors of other families. When we asked grantees how to offer culturally competent support, the following common themes emerged:

- Recruit staff who are family members of CYSCHN from diverse communities to act as cultural brokers for outreach and the provision of Center services;
- Make information and assistance available in languages other than English;
- Address latent distrust of the health and social services systems through reliable and consistent services;
- Build relationships with trusted and well-connected families and community organizations; and
- Look to families to define their own specific information and service needs.

In their efforts to serve a culturally-diverse population, Family to Family Centers use a variety of strategies to pursue these goals, including interpreter services, cultural peers as volunteers, and community outreach. In addition, several grantees shared with us specific innovative practices that had facilitated their outreach and service to diverse communities. These are described in greater detail below and include:

- Focused training and outreach for organizations serving minority populations;
- Developing a cultural competence coalition;
- Establishing a multicultural center; and
- Building trust through sharing information.

Focused Training and Outreach for Organizations Serving Minority Populations

Serving a multicultural population effectively sometimes requires focused and tailored efforts to reach specific subpopulations. This can include not only outreach to families within these populations, but initiatives to connect with the providers and organizations that serve them as well. Making sure that these organizations know about the existence and capabilities of Family to Family Centers allows the Centers to connect more effectively with minority families of CYSCHN who might not otherwise seek out their support.

¹⁷ <http://bhpr.hrsa.gov/diversity/culturalcomp.htm>

The *Statewide Parent Advocacy Network (SPAN)* has developed a successful partnership with a coalition of community-based organizations to provide just such a focused connection with the Hispanic community in New Jersey. The Hispanic Directors Association (HDA) comprises 33 member organizations that serve the Hispanic community statewide. Leadership from the association approached *SPAN* to provide training to its members, which it funds through a grant provided by New Jersey's Department of Human Services.¹⁸ The center is currently conducting a series of workshops to train staff from these non-profit organizations about the unique needs of CYSHCN and the supports available to them in the state. For example, the first all-day workshop focused on identifying special needs, accessing resources, and understanding families' rights. Long-term training goals are 1) to improve Latino organizations' ability to provide information, services, and assistance to families with CYSHCN, 2) to increase these organizations' knowledge of resources available through SPAN, and 3) to increase the organizations' comfort level in connecting families with *SPAN*.

SPAN is also cooperating with other disability organizations to conduct conferences that bring together disability organizations and community-based organizations that serve diverse families. The center uses its relationship with organizations like United Way grantees, Head Start agencies, and community health clinics to identify appropriate conference participants. The goal of these partnerships is to share best practices for serving African-American, Latino, and Asian families with CYSHCN and increase the capacity of these organizations to effectively serve such families seeking their services. In addition, *SPAN* believes these forums will increase cultural competence among disability organizations. In 2005, *SPAN* and other organizations held a two-day forum focusing on Latino organizations; future forums will focus on African-American families and South Asian families.

Under the leadership of its director, *Family Voices of North Dakota* also has developed several focused outreach initiatives to increase accessibility for cultural, ethnic and racial minorities, by connecting with the providers that serve these groups. For example, prior to the CMS grant, *Family Voices of North Dakota* staff joined other disability organizations in an all-day meeting with a Fargo-based cultural resources center that provides information and assistance to people not fluent in English. When funded through CMS, additional direct outreach to interpreters from several of Fargo's immigrant communities resulted in referrals from these interpreters to families with CYSHCN. Interpreters serve as liaisons between *Family Voices of North Dakota* and the families to ensure families understand the information they receive and that all their questions are answered. Finally, staff from *Family Voices of North Dakota* presented before the local human rights commission in Fargo to connect with other organizations that work with cultural minorities.

A particular focus of *Family Voices of North Dakota's* cultural outreach has been with providers serving American Indian families. The director promotes the center's services to staff at reservation-based Early Intervention programs, Head Start programs, clinics, and Indian Health Services. This word-of-mouth approach has led to an increase in referrals from American Indian Communities. To strengthen this relationship, *Family Voices of North Dakota's* board includes American Indian family members in order to ensure their perspective informs key decisions.

¹⁸ Hispanic Director's Association, July 21, 2005 <http://www.hdanj.org/teachers.html>

Contact Information:

❖ ***Family Voices of North Dakota***

Donene Feist

fvnd@drtel.net

(701) 493-2634

www.geocities.com/ndfv

❖ ***SPAN*** (provided above)

Developing a Cultural Competence Coalition

Cultural competence – the skills and attitudes necessary to effectively work with a culturally diverse population – is a capability that can be enhanced through direct training. Teaching staff, families, and stakeholders the tools necessary to reach out and serve people from different backgrounds is another way Family to Family Centers can strengthen their impact on all families with CYSHCN.

In order to improve cultural competence among community leaders supporting CYSHCN in Florida, the *Florida Institute for Family Integration (FIFI)* held a two-day cultural competence training for family leaders and government policymakers. For the training, *FIFI* connected with the Georgetown University Center for Cultural Competence, which is funded by MCHB to help CYSHCN programs develop and implement a culturally competent service delivery through training, technical assistance, and consulting. Other organizations may qualify for assistance from Georgetown if they receive Title V funding.¹⁹ *FIFI* is currently one of three family organizations currently receiving on-site assistance.

FIFI's training session had a total of 22 people, including two youth with special health care needs. The training aimed to create leaders in cultural competence across the state without building defensiveness or resistance. Training topics included moving beyond cultural barriers, handling difficult situations, and building leadership capacity to serve as cultural brokers with various populations. After the training, a listserv was established by the attendees to share experiences and exchange strategies for providing culturally-appropriate services.

Contact Information:

❖ ***Florida Institute for Family Involvement*** (provided above)

Establishing a Multicultural Center

Another innovative way of enhancing Family to Family Centers' cultural competence is to create a physical space devoted specifically to serving families with diverse cultural backgrounds. In Minnesota, the *Parent Advocacy Coalition for Educational Rights (PACER)* has created a multicultural center that provides information and assistance to diverse communities. Staff

¹⁹ More information about this program can be found at <http://gucchd.georgetown.edu/nccc/>

members from the center also translate educational materials into several languages. Because some families are more comfortable with home visits, staff members from the multicultural center visit many families in their homes to offer information and assistance. The multicultural center supports both the Family to Family Center and *PACER's* Parent Training and Information (PTI) Center. The PTI Center provides parents of children with disabilities training and information to facilitate their involvement in helping children meet developmental, functional, and academic goals.

Contact Information:

❖ ***Parent Advocacy Coalition for Educational Rights (PACER)***

John Hoffman

jhoffman@pacer.org

Amy Dawson

amy.dawson@pacer.org

(952) 838-9000

www.pacer.org

Building Trust through Sharing Information

Cultural competence in an organization recognizes that families have different preferences regarding communication, and different attitudes about disability, which may vary by cultural group. Just as some families may prefer to be visited at home, others may be reluctant to admit they have a child with a disability or special need due to cultural values and norms. In California, *Family Voices of CA* council members recognize this phenomenon, and have provided a training series with general information on the health care system in general, such as health care financing options and tips for communicating with physicians. This allows trainers to build trust and rapport with families who are wary of discussing their child's disability. After building rapport, the organization can then present information specifically relevant to CYSHCN.

Contact Information:

❖ ***Family Voices of CA***

Linda Vossler-Swan

lswan@supportforfamilies.org

415-282-7494

www.supportforfamilies.org

Facilitating the Transition to Adulthood

The transition from support systems designed for CYSCHN to those for adults with disabilities can be difficult for families. Relationships change as many youth move away from home, pursue a job or higher education, and exercise self-determination in their day-to-day life. In addition, youth with special health care needs often have access to fewer services once they reach adulthood. For example, the education system is no longer required to provide supports and Medicaid participants no longer receive the comprehensive Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit. While facilitating this transition is not a primary focus of all Family to Family Centers, we identified at least two grantees that have developed specific and innovative strategies in mentoring and training to address the unique needs of youth with special health care needs as they move into adulthood.

Mentoring through Youth Leadership Groups

As young people with special health care needs prepare to assume greater control over and responsibility for their own care, self-advocacy skills become increasingly important. Other youth with these skills can be excellent mentors, similar to the role of experienced parents of CYSCHN as Family to Family Center volunteers. To link youth together, *Maine Parent Federation* has established and worked with youth leadership groups in several regions of the state. Regional coordinators from the *Maine Parent Federation*, in partnership with the Committee on Transition, Maine's interdepartmental system for transition planning, identify youth for participation in the youth leadership groups. Membership includes experienced youth who have special health care needs, matched with other youths who ask for or need support.

Two of the regional groups have been particularly successful in developing peer-mentoring relationships and encouraging self-advocacy and leadership. The Downeast Youth Leadership Program, in the easternmost portion of Maine, has developed a training curriculum to help youth develop leadership and self-advocacy skills. Parents in this same region coordinated a daylong workshop on Pediatric Mood Disorders, designed specifically to help professionals develop or improve their skills when working with children and youth with depression and bipolar disorder. Jointly-sponsored by the Maine Medical Center and *Maine Parent Federation*, this successful event has since been replicated in four other locations around the state.

Youth in the Mid-Coast region of Maine helped develop a training video through their youth leadership group that shows examples of domestic violence among people with disabilities. A committee that consisted of youth with disabilities, parents and professionals developed a curriculum to inform both caregivers and individuals with disabilities about domestic violence and the varying forms that it can take. This training was designed as a train-the-trainer model and youth are the lead trainers offering the training across the state.

Contact Information:

❖ **Maine Parent Federation**

Bev Baker

bbaker@mpf.org

(207) 623-2144

<http://www.mpf.org/>

Conducting Small Group Self-Determination Trainings

Like mentoring, training is another effective way to develop self-advocacy skills among youth with special health care needs moving into adulthood. To provide such training, West Virginia's Family to Family Resource Center, the *People's Advocacy, Information, and Resource Services (PAIRS)*, collaborates with the Mountain State People's Alliance to discuss transition and self-determination with families of CYSHCN. The Mountain State People's Alliance and *PAIRS* hold meetings where adults with disabilities talk to small groups of families with CYSHCN. This provides families with examples of how people are positively integrated into the community. At the end of each meeting, families discuss and plan next steps to facilitate their children's independence and self-determination. *PAIRS* emphasize two key issues when helping families plan for the future: children need to have choices and need to develop meaningful friendships that will lead to strong circles of support.

The Mountain State People's Alliance and *PAIRS* used this partnership as an additional opportunity to provide youth with information about transitioning to adulthood. Together, they developed a few focused sessions for the Health Education and Social Studies curricula of local schools. The health education component of the training focuses on self-care, decision making, and self-advocacy for both long-term and short-term healthcare. These training sessions serve the double purpose of helping students gain knowledge and self-determination on health and disability issues, and allowing schools to meet the criteria of promoting health literacy among their students.

Contact Information:

❖ **People's Advocacy, Information, and Resource Services (PAIRS)**

Scott Miller

scottsam@verizon.net

(304) 645-6356

www.letsgetalifewv.org

Ensuring Sustainability through Multiple Funding Sources

All the good work done by Family to Family Centers in the last several years will be lost if the Centers themselves are unable to ensure their long-term sustainability. Moving beyond federal funding will be important for the Centers' long-term sustainability. Some Family to Family Centers have already obtained funding to continue or expand outreach and information dissemination. Several Centers have grants or contracts with their state's CYSHCN program to continue the specialized trainings that Family to Family Centers provide, such as educating families and providers regarding a medical home. Selected Centers have also been creative in securing additional funding sources to work towards maintaining long-term viability. These additional funding sources, described in detail below, include:

- Medicaid reimbursement for case management;
- Private foundation grants;
- State funds for provider monitoring; and
- Contracts with managed care organizations.

Medicaid Reimbursement for Case Management

The population served by Family to Family Centers includes many Medicaid recipients, due to the involved and costly nature of their specialized health care needs. Providing care coordination for Medicaid benefits is one way for Centers to secure funding for a service compatible with their core mission of connecting CYSHCN with appropriate health care services. *Stone Soup Group* was able to do this by becoming a certified care coordination provider in Alaska, where care coordination is a service in the state's Medicaid waiver for people with developmental disabilities. This certification requires a higher level of information, service and assistance than Family to Family Centers typically provide. *Stone Soup Group* is currently working with the State Title V program, and officials in State Medicaid to successfully bill for care coordination services. In addition, *Stone Soup group* is currently working under grant and contract funding through the Title V program to provide case management functions, using the Center's Parent Navigation model.

Contact Information:

- ❖ *Stone Soup Group* (provided above)

Private Foundations Grants

Support from one or more private sources is another promising mechanism to enhance federal funding. In California, *Family Voices of CA* is made up of a group of 11 parent centers from around the state. Statewide foundation grants have funded *Family Voices of CA's* statewide activities including a strategic plan, while individual members of the Council are able to attain local foundation grants to support local projects such as parent-to-parent support in hospitals. *Family Voices of CA's* ability to secure private funding was enhanced by a strategic plan that highlighted the need for information, education and ensuring families voices are heard. *Family Voices of CA* provides evaluations throughout projects it implements. Evaluations allow *Family Voices of CA* to measure the impact of information on the families and professionals they assist

and to provide feedback to the funding organizations. *Family Voices of CA* council members have also been successful in obtaining funding from a variety of other sources including: local corporations, fundraisers, and local, county and state government.

Contact Information:

❖ *Family Voices of CA*
(provided above)

State Funds for Provider Monitoring

State health and social services monies represent an additional funding source accessed by several Family to Family Centers. *Family Voices of Louisiana* was able to secure state funding via a contract with the state's Office of Mental Health to monitor mental health hospitals and clinics for cultural competence and family friendliness. *Family Voices of Louisiana* visits the agencies and writes reports based on consumer and staff interviews and in-person observations. While the monitoring contract does not pay for the information and assistance services the center provides, it does increase overall funding and plays an important role in introducing providers and consumers to the organization, thus enhancing the Center's outreach.

Contact Information:

❖ *Family Voices of Louisiana*
Phyllis Landry-Ratcliff
familyla@bellsouth.net
(504) 299-9176

Contracts with Managed Care Organizations

Managed care organizations (MCOs), with their comprehensive approach to providing and coordinating health care services, have complementary goals to the work of Family to Family Centers in helping families with CYSHCN access the full range of needed services. This relationship bore fruit in Indiana, where the *Indiana Parent Information Network (IPIN)* provides information, peer support, and training to families and professionals in order to better serve families with CYSHCN. Recognizing the value of these services, two Medicaid managed care organizations (MCOs) contract with *IPIN* and pay them for the services they are providing to MCO members.

This arrangement began with communication between the former director of *IPIN* and the Medical Director at MD Wise, a not-for-profit Medicaid MCO. Staff at MD Wise found *IPIN's* services invaluable and they wanted to underwrite some of *IPIN's* operational costs for serving their families. MD Wise pays *IPIN* a monthly rate, and the two organizations have a HIPAA business associate contract that allows MD Wise to release referrals to *IPIN*, but holds the center accountable for handling private health information according to HIPAA regulations. This contract allows *IPIN* to initiate contact to MD Wise members once they have received a referral from the family's case manager. *IPIN's* second MCO contract with Harmony, a for-profit MCO,

developed after a staff member attended an *IPIN* training. *IPIN* spoke with the Harmony several times afterwards and agreed on a contract option similar to MD Wise, with the exception that the MCO pays *IPIN* on a per family basis.

This relationship has been mutually beneficial to all partners. In addition to providing *IPIN* with an important source of revenue, the MCOs value the services they are purchasing for families as well as health professionals. *IPIN* helps to increase knowledge and sensitivity among professionals working with families of CYSHCN. *IPIN* also helps reduce over-utilization by providing families with the resources to get the disability, law, health, education and social services they need. *IPIN* staff note, however, that they always work in the best interest of the families, even if it means filing an appeal against the MCO.

Contact Information:

- ❖ *The Indiana Parent Information Network*
Rebecca Kirby
rebecca@ipin.org
317-257-8683
www.ipin.org

Conclusion

Family to Family Centers nationwide provide important information and assistance to families of CYSHCN, as well as the professionals who care for them, often with very limited staff and resources. As the number of such organizations continues to grow, new Centers and other organizations performing similar activities can benefit from the creative and promising ways existing Centers have strengthened their capacity and overcome funding and other challenges. And, all Centers must pursue efficiency and sustainability to continue their important work. This report describes several particularly innovative examples of how select Centers are accomplishing both these goals. Both new and established Family to Family Centers, as well as other similar organizations serving families of CYSHCN, may want to capitalize on these practices to expand and improve their abilities to reach and serve their communities. To this end, Appendix I includes a list of all existing Family to Family Centers funded by CMS and HRSA, all of whom are willing to share information about their organizations. In addition, many of the products developed by individual CMS grantees are available at www.hcbs.org.

Appendix I

Appendix I: Family to Family Health Care and Information Centers

Alaska	<i>Stone Soup Group</i> http://www.stonesoupgroup.org/f2f/ Katy Parrish 907-561-3701
Arizona	<i>Raising Special Kids</i> http://www.raisingpecialkids.org/ Wendy Benz 602-242-4366
California	<i>Support for Families of Children with Disabilities</i> http://www.supportforfamilies.org Juno Duenas 415-282-7494
Colorado	<i>Cerebral Palsy of Colorado</i> http://www.familyvoicesco.org Christy Blakely 303-973-5780
Connecticut	<i>Favor, Inc.</i> http://www.favor-ct.org Molly Cole 860-563-3232 X201
Florida	<i>Florida Institute for Family Involvement</i> http://www.fifionline.org/ Conni Wells 850-926-4230
Idaho	<i>Idaho Parent Unlimited, Inc.</i> http://www.ipulidaho.org/ Evelyn Mason 208-342-5885
Illinois	<i>The Arc of Illinois</i> http://www.familyvoices.org/st/IL.htm Faye Manaster 708-206-1930
Indiana	<i>The Indiana Parent Information Network, Inc.</i> http://www.ipin.org/ Rebecca Kirby 317-257-8683

Appendix I

Iowa	<i>Family Voices at Access for Special Kids</i> http://www.askresource.org 515-243-1713
Kentucky	<i>The Arc of Kentucky, Inc.</i> http://www.arcofky.org Patty Dempsey 502-875-5225
Louisiana	<i>Family Voices of Louisiana, Inc.</i> http://www.familyvoices.org/F2F.htm Phyllis Landry-Ratcliff 504-299-9176
Maine	<i>Maine Parent Federation, Inc.</i> http://www.linkmaine.org Bev Baker 207-623-2144
Maryland	<i>The Parents' Place of Maryland, Inc.</i> http://www.ppmmd.org/ Kim McKay 410-768-9100
Massachusetts	<i>Federation for Children with Special Needs</i> http://www.massfamilyvoices.org/ Beth Dworetzky 401-783-4058
Michigan	<i>SE Michigan Health Assoc. Parent Participation Program</i> Mary Marin 517-241-7197
Minnesota	<i>PACER Center</i> http://www.pacer.org/ Carolyn Allshouse 651-281-9970
Montana	<i>Parents, Let's Unite for Kids</i> http://www.pluk.org/ Dennis Moore 406-255-0540

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Nevada	<i>Family TIES of Nevada, Inc.</i> http://www.familytiesnv.org/ Marcia O'Malley 775-823-9500
New Hampshire	<i>NH Coalition for Citizens with Disabilities</i> http://www.nhfv.org Martha-Jean Madison Terry Ohlson-Madison 603-271-4525 603-271-8180
New Jersey	<i>Statewide Parent Advocacy Network of NJ, Inc.</i> http://www.spannj.org/ Diana Autin 973-642-8100 X105
New Mexico	<i>Parents Reaching Out for Help, Inc.</i> http://www.Parentsreachingout.org David Murchio 505-247-0192
New York	<i>Parent to Parent of New York, Inc.</i> http://www.parenttoparentnys.org/ Jan Fitzgerald 518-359-3006
North Carolina	<i>Exceptional Children's Assistance Center</i> http://www.ecac-parentcenter.org/ Grace Sisco 704-892-1321 X11
North Dakota	<i>Family Voices of North Dakota, Inc.</i> http://www.geocities.com/ndfv/ Donene Feist 701-493-2634
Oregon	<i>Family Action Coalition Team</i> Becky Adelman 503-494-7657
Rhode Island	<i>RI Parent Information Network</i> http://www.ripin.org/ Dawn Wardyga 401-727-4144

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South Carolina	<i>Family Connection of South Carolina, Inc.</i> http://www.familyconnectionsc.org Pat Head 803-252-0914
South Dakota	<i>South Dakota Parent Connection</i> http://www.sdparent.org/ Dina Castro 605-361-3171
Tennessee	<i>Family Voices of Tennessee</i> http://www.tndisability.org/ Dara Howe 615-383-9442 X13
Texas	<i>Texas Parent to Parent</i> http://www.main.org/txp2p/ Laura Warren 512-458-8600
Utah	<i>Utah Parent Center</i> http://www.utahfamilyvoices.org/ Gina Pola-Money 801-808-4420
Vermont	<i>Parent to Parent of Vermont</i> http://www.partoparvt.org/ Hilary Melton 802-764-5290 X19
Virginia	<i>Medical Home Plus, Inc.</i> http://www.va-info.org Maureen Mitchell 804-264-8428
Washington	<i>Washington PAVE</i> http://www.washingtonpave.org/ Cassie Johnston 253-565-2266
West Virginia	<i>WUPTI, Inc.</i> http://www.letsgetalifewv.org Scott Miller 304-645-6356

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Wisconsin

Family Voices of Wisconsin

<http://www.wfv.org/>

Liz Hecht

608-263-7148