

Part 5

Family to Family Health Care Information and Education Center Grantees

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Section One. Overview

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

Parents often lack knowledge about the wide range of services and supports for CYSHCN and have little experience dealing with the health and long-term services and supports systems and the health insurance bureaucracy. Family to Family Health Information Centers (hereafter, FHICs) provide a critically important service by educating parents about available services and helping them navigate complex systems and bureaucracies. In addition to helping families make informed choices about health care in order to improve their children’s health and functional outcomes, FHICs also promote the philosophy of family-centered care, individual- and family-directed supports, and the adoption of the medical home concept through education and training initiatives targeted to health care and other service providers.¹⁰

In 2001, as part of the federal New Freedom Initiative to promote community living for persons with disabilities, federal agencies were instructed to work together to eliminate barriers to community living. In response, the Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB), and CMS established grant programs to help develop FHICs. Funding for these centers was approved as part of the Family Opportunity Act (FOA), which was signed into law in 2006 as part of the Deficit Reduction Act of 2005. As of June 2008, 41 states/territories had FOA-funded FHICs with primary funding support from the MCHB, which also funds the national organization Family Voices, and the National Center for Family/Professional Partnerships to provide technical assistance to these 41 FHICs. It is anticipated that all states and the District of Columbia will have FOA-funded FHICs by 2009.

¹⁰ In a medical home, a pediatric clinician works in partnership with the family and/or patient to ensure that all medical and non-medical needs are met. Through this partnership, the pediatric clinician can help the family and patient obtain and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the patient and family. See <http://www.medicalhomeinfo.org/> for more information.

In FY 2003, CMS awarded grants to organizations in nine states to develop Family to Family Health Information Centers (see Exhibit 5-1)

Exhibit 5-1. FY 2003 Family to Family Grantees

Alaska— <i>Stone Soup Group</i>	New Jersey— <i>Statewide Parent Advocacy Network, Inc.</i>
Colorado— <i>Family Voices Colorado</i>	Nevada— <i>Family TIES of Nevada, Inc.</i>
Indiana— <i>About Special Kids</i>	South Dakota— <i>South Dakota Parent Connection, Inc.</i>
Maryland— <i>The Parents' Place of Maryland</i>	Wisconsin— <i>Family Voices of Wisconsin</i>
Montana— <i>Parents, Let's Unite for Kids</i>	

The amounts of the awards to the Family to Family Health Care Information and Education Center (FTF) Grantees were less than those given to other Systems Change Grantees, reflecting the narrower scope of their goals (i.e., not to bring about systems change but to establish a Family to Family Health Information Center).

Results

All of the Grantees established a Family to Family Health Information Center as part of their existing organizational structure. For many of the organizations that received FTF grants, developing an FHIC required an expansion of their original mission. For example, the Parents' Place of Maryland (PPMD) is a nonprofit family-centered organization, which was established in 1991 to enhance the ability of CYSHCN to participate as fully as possible in home, school, and community life by providing education, information and referral, and support for them and their families. Prior to receiving an FTF grant, PPMD had focused on providing support and training for families on their rights in special education. The grant enabled PPMD to expand its mission and its staff's capacity to help families access health care.

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

Many of the Grantees established partnerships with other organizations that serve CYSHCN. For example, the Grantee in New Jersey, the Statewide Parent Advocacy Network, Inc. (SPAN), is a family education and advocacy agency. The new FHIC enabled its staff and

volunteer Resource Parents to develop partnerships with hospitals, clinics, mental health facilities, family support organizations, immigrant networks, and other organizations, thereby facilitating the dissemination of information and support for families statewide.

Once the South Dakota Parent Connection, Inc. (SDPC), established an FHIC, FHIC staff established partnerships and working relationships with health care providers, the two major hospital systems in South Dakota, and state agencies. Establishing the FHIC expanded SDPC's focus to include providing information, training, and other resources in the area of health care for CYSHCN.

The Alaskan FHIC established strong collaborative relationships with many organizations and agencies concerned with children's health, including The Governor's Council on Disabilities and Special Education, The Children's Hospital at Providence Hospital, The Disability Law Center of Alaska, the University of Alaska Center for Human Development, Anchorage School District, the Alaska Autism Resource Center, the Alaska Youth and Family Network, and many others.

Once established, the new FHICs engaged in a wide range of activities that assisted thousands of CYSHCN and their families as well as the health care professionals that serve them. These activities are discussed below.

Providing Information and Referral Services

Grantees provided extensive one-on-one information and referral services to thousands of families and hundreds of professionals during the grant period. For example, program staff and volunteers in Alaska directly or indirectly assisted 1,741 parents and 221 professionals. The information provided has empowered parents and caregivers to make more informed decisions regarding the most appropriate care and treatment for their child. FHIC staff in Maryland assisted 2,902 families through phone calls, e-mails, and in-person meetings.

Issues, problems, or concerns that spurred family contact with FHIC staff included a need for information about public benefits, eligibility for services, funding for medical services, and access to appropriate services and nonmedical services. Staff advised families, made referrals, or helped them with the referral process, and attended meetings with parents and agencies or providers. The Grantee conducted a survey in which about 96 percent of parents reported that the information and assistance they received from FHIC staff made them more knowledgeable about how to work with providers; and about 84 percent of parents reported that their child received more appropriate services.

Developing Informational Materials

Grantees developed a range of print and web-based materials, including newsletters, brochures, information packets, fact sheets, resource notebooks, and care notebooks, to

provide a system to organize information about a child's medical history, daily activities, appointments, and medical expenses. To meet the needs of non-English-speaking families, many FHICs translate their materials into languages common in their states, such as Spanish, Portuguese, and Chinese.

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

Providing Education and Training

Grantees provided in-depth education in workshops and at conferences, and some facilitated family participation by providing modest subsidies for travel expenses and respite care. Sample topics covered include Medicaid eligibility and benefits and transitioning from child health and support services to the adult service system. To serve families who were unable to attend trainings in person, many FHICs used technology such as web-based conferences, teleconferences, and videoconferences. To reach the greatest number of families possible, they also employed train-the-trainer educational approaches, so those participating could share what they had learned with other families in their communities.

In addition to providing education and training for families, FHICs also provide programs for health professionals, including physicians, nurses, and social workers, and for medical and nursing students. Some of the workshops and seminars have been approved for continuing education credits.

Improving Programs and Informing Policies

Policy makers and program administrators may not understand how specific policies and program provisions affect service delivery. Consequently, educating policy makers and other stakeholders about the needs of CYSHCN and the challenges their families face is critical to ensuring the quality and timely receipt of services. Several Grantees engaged in activities to educate policy makers about program and policy issues important to families of CYSHCN.

For example, in collaboration with the Survival Coalition of Wisconsin, Family Voices of Wisconsin developed a series of proposals for the FY 2007–FY 2009 biennial state budget that included funding to address waiting lists for children's long-term services and supports and to develop the infrastructure to provide information, assistance, and advocacy services for children with disabilities and special health care needs. Their efforts resulted in the inclusion of \$4.7 million to address waiting lists in Year 1 and \$4.8 million in Year 2, which

was the first significant increase in funding for children's long-term services and supports in 12 years. Federal sponsorship of the FHICs has helped them to play a meaningful role in the policy process by increasing their visibility and perceived legitimacy.

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

The purpose of the FTF grants was to provide seed money to help establish a Family to Family Health Information Center. Grantees had to develop plans to sustain the new FHIC after the grants ended. The national organization Family Voices, funded by CMS to furnish technical assistance to the FTF Grantees, provided sustainability tool kits and organized conference calls to discuss approaches and options. Grantees pursued several strategies, including applying for new grants, alone or in partnership with other organizations, and several received a grant from the federal Maternal and Child Health Bureau.

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

Lessons Learned

Grantees cited a number of lessons learned throughout the grant period that may be helpful to organizations seeking to aid CYSHCN and their families, generally, and to develop and operate FHICs, specifically.

- It is difficult to get families and professionals to attend in-person trainings on public funding for services for CYSHCN (e.g., Medicaid waivers) despite their expressed interest in the topic and the availability of financial assistance to support attendance. This is likely due to professionals' very busy schedules and families' caregiving and work responsibilities. Using technology and web-based activities for providing information, education, and training can help reach families and professionals who cannot attend in-person meetings.
- Prioritizing the development of leadership skills for parents and families of CYSHCN is a key strategy for bringing about systems change. Training develops parent leadership: first to advocate for their own child, then to support and advocate for other children and families, and then to participate in systems change activities.

- Developing a dedicated and well-informed parent trainer network requires a significant level of support and nurturing. Because of the complexity of both the health care system for children with disabilities and of insurance coverage issues, family educators may require extensive training and mentoring to gain the expertise needed to support other families. Active mentoring is essential for parents conducting outreach with unfamiliar communities.
- Using focus groups is an effective strategy for identifying the needs and strengths of families from diverse backgrounds in order to develop supports and services to address their needs and to build on their strengths. Using cultural brokers to work with families from diverse cultures and creating partnerships with community-based, immigrant, and other organizations can maximize outreach and effectiveness.
- Bringing state agencies together to address issues strategically and share scarce resources is essential to increase access to and the availability of services for CYSHCN. Children's disabilities and health care needs have an impact on many other areas, such as mental health and education, and the needs of families of CYSHCN also span many areas, including housing, employment, and public benefits.

No organizations or agencies have all the resources and expertise needed to address issues in all of these areas for families statewide. Collaboration is key, and working together has much more impact than working individually. Collaborative relationships with organizations and entities with similar goals can leverage resources, reduce duplication of efforts, and develop effective shared strategies for providing information on services and supports to families of CYSHCN.

- When beginning systems change activities, involving the people who are directly affected—particularly those with least access to services and supports, such as low-income ethnic minorities—is essential to identify what is and is not working and why; to determine how to address problems and barriers; and to develop, implement, and evaluate solutions. Involving stakeholders from the beginning and conducting outreach in communities are essential components of building a Family to Family Health Information Center.
- Although it is important to provide data to bring about changes in policies affecting CYSHCN, providing personal information about individuals who need services is also a very powerful and effective educational approach. For example, when advocating for an increase in waiver slots, FHIC staff produced a booklet that showed children who had been on the waiver waiting list for as long as 6 years, along with a short story about them.

Recommendations

Grantees made several recommendations for states to better meet the needs of CYSHCN and their families. Although their recommendations were aimed at their own states, they are relevant for other states as well.

Policy Issues

- The state should streamline the Medicaid and Children’s Health Insurance Program eligibility process for all presumptively eligible categories of children. Streamlining the process and using other means to identify children in low-income categories (such as through the free and reduced school lunch programs) can help children access health services.
- A significant number of South Dakota’s CYSHCN are uninsured and underinsured—higher than the national average. A Medicaid buy-in option would help working families who have private insurance but whose coverage does not meet their child’s health needs. Enacting the Family Opportunity Act in South Dakota would help families whose income fluctuates or is slightly over the income guidelines for the State Children’s Health Insurance Program and Medicaid, by establishing a sliding scale for eligibility.
- Medicaid policy focuses on the individual receiving the services, which leads to a lack of flexibility in meeting the needs of CYSHCN living with their families, particularly to support the health of family members and their ability to care for their child at home. Medicaid policy should allow families of children under 18 with significant disabilities to be reimbursed for providing personal care and other expenses incurred to care for their child.
- One state has converted most of its state programs serving CYSHCN to Medicaid waiver programs in order to secure federal matching funds. However, many individuals who need services are ineligible because they do not meet the waiver program’s level-of-care criteria. To meet their needs, the state should increase service funding for non-Medicaid eligible individuals and should decrease the stringency of the waiver level-of-care criteria.
- To correct the continued institutional bias in Medicaid and state policies, home and community-based services should be mandatory—and waivers should be required for *institutional* services.

Services and Supports

- As Wisconsin continues to expand Aging and Disability Resource Centers, the disparity between resources dedicated to adults with disabilities and CYSHCN has become more apparent. The Department of Health and Family Services has made a commitment to end waiting lists for community-based services and supports for adults of all ages with disabilities, but no such commitment has been made to children and their families. The State needs a single point of entry coupled with high-quality information in the system that serves CYSHCN.
- The state should provide incentives to create a Durable Medical Equipment recycle program for children, as well as incentives to provide a cash-and-carry process for transitioning youth to become independent after completing Vocational Rehabilitation and transition programs. A cash-and-carry process would allow individuals to take

services and equipment to their place of employment through an agreement between departments serving the transitioning population.

- The state and the federal government should increase access to and the availability of services through public programs for CYSHCN, and a comprehensive range of services should be available statewide.
- Parents are a critical partner in the “workforce” that supports CYSHCN yet often do not have access to the information they need to support their child/young adult’s needs. Parents need access to high-quality training and information to be effective advocates, partners, and allies with the professionals with whom they work. This training, support, and leadership development needs to be an integral component of the infrastructure of state systems.

Section Two. Individual FTF Grant Summaries

Alaska

Primary Purpose

The grant's primary purpose was to develop a Family to Family Health Information Center (FHIC) to (1) serve as a statewide information clearinghouse for families of children and youth from birth to age 22 with special health care needs (CYSHCN); (2) create an interactive, statewide peer-to-peer network and support forum for families caring for CYSHCN; and (3) develop sustainable funding for the ongoing operation of the FHIC.

The grant was awarded to the Stone Soup Group, an Anchorage-based nonprofit organization that provides information and training for parents of CYSHCN. The Center for Human Development at the University of Alaska Anchorage and the Governor's Council on Disabilities and Special Education were subcontractors on the grant.

Results

- Grant staff developed training programs and workshops to provide parents with information on services available for CYSHCN and how to navigate the state and federal service systems. Throughout the grant period, 233 community trainings, workshops, and meetings were conducted with 3,858 participants.
- The Grantee created a statewide advisory group of parents and professionals to serve as a resource to families of CYSHCN. Members of this advisory group educate providers and other parents about the need for a family-centered perspective when caring for CYSHCN. The advisory group also developed a funding sustainability plan, which describes approaches for sustaining the FHIC beyond the grant period.
- The Grantee established a fully operational Family to Family Health Information Center and created a statewide information clearinghouse to provide printed and digital information on resources for families of CYSHCN. The FHIC now has an established base of parent volunteers who work directly with Alaskan families as a parent-to-parent network of support. During the grant period, program staff and volunteers directly or indirectly assisted 1,741 parents and 221 professionals. The information provided has empowered parents and caregivers to make more informed decisions regarding the most appropriate care and treatment for their child.
- The FHIC developed strong collaborations with many organizations and agencies concerned with children's health, including The Governor's Council on Disabilities and Special Education, The Children's Hospital at Providence Hospital, The Disability Law Center of Alaska, the University of Alaska Center for Human Development, Anchorage School District, the Alaska Autism Resource Center, the Alaska Youth and Family Network, and many others. These continuing partnerships will significantly benefit CYSHCN across Alaska. Stone Soup Group's website was updated to include additional collaborating agency links and resource information for CYSHCN. (See <http://www.stonesoupgroup.org/index.cfm?section=Links&page=Overview>.)

- As a result of collaboration in statewide advocacy efforts by grant staff, the State has increased the number of Medicaid waiver slots available for children, youth, and adults with developmental disabilities. The increase has reduced the number of individuals waiting for Medicaid services from about 1,400 to 900. The State plans to further reduce the number on the waiting list.
- The Stone Soup Group secured annual funding of \$108,000 for 2 years from the Alaskan Mental Health Trust Authority to expand a peer-to-peer network targeting rural Alaskan communities.

Lessons Learned and Recommendations

- Stakeholders should use collaborative relationships to leverage resources and reduce duplication of efforts, and to develop effective shared strategies for providing information on available services and supports to families.
- The State has converted most state programs serving CYSHCN to Medicaid waiver programs in order to secure federal matching funds. Many individuals who need services are ineligible because they do not meet the required level-of-care criteria for waiver eligibility. To meet their needs, the State should increase service funding for non-Medicaid eligible individuals and also decrease the stringency of the waiver level-of-care criteria.

Products

Outreach Materials

- Grant staff produced a brochure entitled *Alaska Statewide Parent-to-Parent Support Network*, and the *Stone Soup Group Agency Brochure* to increase awareness of the FHIC among parents of CYSHCN.
- Grant staff developed *Soup of the Week*, a web-based newsletter offering information on current community and statewide trainings, programs, and ongoing policy updates. The newsletter is distributed to 1,592 subscribers.

Educational Materials

Grant staff created Disability Resource Packets on 22 individual topics, and developed an FHIC Resource lending library with 678 titles available in digital and print format.

Colorado

Primary Purpose

The grant's primary purpose was to develop a Family to Family Health Care Information and Education Center (FHIC) and establish a statewide network of parent professionals who will (1) improve access to information about health care systems and community resources, and help other parents to effectively navigate these systems and use these resources; (2) disseminate new and current information to families of children and youth with special health care needs (CYSHCN), service providers, and advocates; and (3) evaluate access to, use of, and satisfaction with the quality of health systems information.

The grant was awarded to Family Voices Colorado, which is a chapter of the national, grassroots organization whose primary goal is to ensure that children's health is addressed when changes are made in public and private health care systems. Colorado's Health Care Program (HCP) for Children with Special Needs was a subcontractor on the grant.

Results

- Family Voices Colorado established a Family to Family Health Care Information and Education Center as a part of its operating structure. During the grant period, staff conducted outreach and provided information to more than 2,300 families of CYSHCN through a toll-free phone line and via e-mail, and distributed more than 6,000 pieces of informational materials. They also created a hotline for providers to call for information on resources for CYSHCN.
- The FHIC staff, in collaboration with Colorado's Health Care Program, trained 14 parent leaders in the State's 14 HCP regions to conduct trainings with about 1,200 providers, professionals, and families on issues affecting CYSHCN. They also provided support for other parents, and conducted Medical Home outreach by serving as a resource for providers regarding service and health coverage issues affecting CYSHCN. A process is now in place for outreach throughout Colorado, in particular, to Spanish-speaking populations, for whom materials and trainings have been translated.
- Trained parent leaders became members of several decision-making bodies that address the needs of CYSHCN to ensure that their views are heard and their children's needs addressed. One parent has been appointed to a State Health Reform Commission.
- A statewide FHIC-conducted needs assessment survey of CYSHCN provided information that has helped influence policy decisions affecting CYSHCN. For example, when the state tobacco tax was passed, FHIC staff provided information and education to the legislators about the need for more home and community-based services waiver slots for CYSHCN, which led to the addition of 630 slots.

Lessons Learned and Recommendations

- Although data are necessary for bringing about changes in policies that affect CYSHCN, providing personal information about individuals who need services can be a very powerful and effective approach. When advocating for an increase in waiver slots, FHIC staff produced a booklet that showed children with their waiver waiting list number—some had been on the list for 5 or 6 years—and a short story about them.
- Continued funding is needed for family-driven organizations to do grassroots information and advocacy work.
- Increased funding is needed to provide home and community-based services for ventilator-dependent children who are currently residing in hospitals at much greater cost.
- The State should provide incentives to create a Durable Medical Equipment recycle program for children, as well as incentives to provide a cash-and-carry process for transitioning youth to become independent after completing Vocational Rehabilitation and transition programs. A cash-and-carry process would allow individuals to take services and equipment to their place of employment through an agreement between departments serving the transitional population.
- The State should streamline the Medicaid and Children's Health Insurance Program eligibility process for all presumptively eligible categories of children. Streamlining the process and using other means to identify children in low-income categories (such as through the free and reduced school lunch programs) can help children access health services.

Products

Outreach Materials

Grant staff developed and distributed outreach materials that contain information about the FHIC, including the services offered and a toll-free number.

Educational Materials

FHIC staff produced training DVDs covering a variety of topics, including self-determination, advocacy and leadership, building medical homes, and navigating health care systems. FHIC staff collaborated with several partners to develop brochures to answer frequently asked questions and other materials on topics such as Medicaid, EPSDT, managed care plans, and SSI. They also developed several forms to help parents and paid caregivers manage and coordinate care for CYSHCN, such as a *Medication Schedule Template*.

Reports

Grant staff prepared a paper based on a Dual Diagnosis Summit convened in January 2007. The document highlights the need for service delivery systems to coordinate services, funding, eligibility, and appeals processes to assist individuals who need services from more than one system simultaneously.

Indiana

Primary Purpose

The grant's primary purpose was to develop a Family to Family Health Care Education and Information Center with the goal of improving the ability of (1) no fewer than 100 families in two regions of the State to care for their children with special health care needs (CSHCN) in the community; and (2) at least 20 health care professionals to provide a medical home for at least 50 families of CSHCN.

The grant was awarded to About Special Kids (ASK), formerly the Indiana Parent Information Network, Inc. ASK implemented the Indiana Parent Education Project in 1990, thus laying the foundation for a statewide network of parents trained as Parent Liaisons to provide information, peer support, and training to other families.

Results

- The Advisory Council for the Family to Family Health Care Education and Information Center—comprising parents and several key professionals from various agencies, organizations, and state offices—provided a forum in which to address issues affecting CSHCN, such as the quality of Medicaid waiver case management, implementation of Medicaid managed care, and training of state education professionals about Medicaid waivers.
- Over the course of the project, grant staff provided families of CSHCN with information about Medicaid services, special education services, and other community resources for CSHCN. They conducted 21 Public Health Care Financing trainings with 165 attendees and provided ongoing support via in-person contact, telephone, and/or e-mail to 427 families of CSHCN, surpassing the goal of reaching 100 families.

Staff also contacted 301 health care professionals who work with CSHCN to educate them about community resources, financing for services, and the medical home concept by using one-on-one conversations, mailed written materials, and the online resource directory.

- Grant staff developed and disseminated 426 packets of information to families and professionals and developed an e-newsletter, which is distributed to 1,841 recipients.
- The grant project led to greater name recognition and awareness of the services offered by ASK and the Family to Family Health Care Education and Information Center. For example, social workers and discharge planners from Kosairs Children's Hospital now frequently consult with an ASK Parent Liaison in that region before a child with special health care needs is discharged home, and include an ASK brochure in the discharge information packet.
- The Grantee developed a new website (<http://www.aboutspecialkids.org>), and the web-based resource directory of family supports was enhanced and updated.

- The Family to Family Health Care Education and Information Center is being sustained through a grant from the federal Maternal and Child Health Bureau. The grant has also enabled ASK to expand its services throughout the State by funding three part-time Parent Liaisons in three regions.

Lessons Learned and Recommendations

It is difficult to get families and professionals to attend in-person trainings on public funding for services for CSHCN (e.g., Medicaid waivers) despite their expressed interest in the topic and the availability of financial assistance to support attendance. This is likely due to professionals' very busy schedules and families' caregiving and work responsibilities. The use of technology and web-based activities for the provision of information, education, and training can reach families and professionals who cannot attend in-person meetings. Therefore, grant staff recommended that anyone interested in providing similar training opportunities develop a web-based curriculum.

Products

Educational Materials

The Family to Family Health Care Education and Information Center Advisory Committee developed a one-page information sheet for educators and school personnel who interact with students with significant disabilities and their families during annual special education case conference meetings. The information sheet provides information about the State's five Medicaid home and community-based services waivers, using a concise and easily understood format: why educators need to know about Medicaid waivers, who might qualify for services, where to apply, and why it is their responsibility to refer families. The Committee developed a statewide version and a regional version representing the regions served by Family to Family Health Care Education and Information Center staff. The information sheet is used by the entire ASK staff in all regions of the State.

Technical Materials

A comprehensive *Guide to Health Insurance* was developed to educate families of CSHCN about services available to their children through private insurance, Medicaid, Children's Special Health Care Services, and Social Security.

Maryland

Primary Purpose

The grant's primary purpose was to ensure that families of children with special health care needs (CSHCN)—including those from minority populations and those with mental and behavioral health disorders—have access to accurate, timely, and culturally appropriate information to enable them to make wise health care decisions.

The grant was awarded to The Parents' Place of Maryland (PPMD), a nonprofit family-centered organization, which was established in 1991 to enhance the ability of CSHCN to participate as fully as possible in home, school, and community life. It provides these families with education, information and referral, technical assistance, and support.

Results

- The Grantee established a Family to Family Health Care Information and Education Center (FHIC) by expanding its mission and its staff's capacity to assist families with access to health care. Previously, PPMD had focused on providing support and training for families on their rights in special education. To better understand access issues related to health care plans and the public and private health care systems, staff conducted focus groups with parents throughout the State. They established a toll-free number for parents to obtain information on health care options, and eight parent educators employed by PPMD were trained to respond to requests for information and support on health care issues.
- FHIC staff assisted 2,902 families over the grant period through phone calls, e-mails, and in-person meetings. Issues, problems, or concerns that spurred family contact with FHIC staff included a need for information about public benefits, eligibility for services, funding for medical services, and access to appropriate services and nonmedical services. Staff advised families, made referrals, or helped them with the referral process, and attended meetings with parents and agencies or providers.

The Grantee conducted a survey in which about 96 percent of parents reported that the information and assistance they received from FHIC staff made them more knowledgeable about how to work with providers; and about 84 percent of parents reported that their child received more appropriate services.

- In response to data collected during the first year of the project, staff focused on increasing supports to ethnically diverse populations in Maryland, assisting significantly more minority families each year (in the first year of the grant, 25 percent more than in previous years, and 43 percent more in the grant's final year). In addition to broadening outreach to diverse communities, the project also focused on reaching out to families with children who had a range of disabilities and special health care needs.
- Project staff conducted outreach to pediatricians, hospitals, and clinics; provided information to community-based family resource centers, school-based health clinics,

homeless shelters, and Head Start programs; and provided training to many agencies and state or community-based organizations in order to increase their skills in effectively assisting families of CSHCN. More than 7,850 contacts with providers were documented during the grant period.

- Project staff developed and conducted an annual Health Leaders training program each year of the grant for 80 parents and family members of CSHCN. The curriculum included information on private health plans and public health programs, enrollment processes, appeals processes, and how to utilize benefits. Graduates of this training program are participating on the Medicaid Advisory Board, several state-level committees, and several community-based policy-making committees. Others have been hired as “Family Navigators” to help families navigate the mental health service system.
- Project staff developed 10 workshops (6 in Spanish) and conducted 160 workshops with more than 3,000 families and providers across the State. They also worked with a web designer to update the PPMD website, published an Email Newsletter that is disseminated to more than 1,500 subscribers monthly, and developed various health fact sheets, brochures, and resource guides for each region of the State.
- Grant activities around the “medical home” model included the creation of a Maryland State Plan for Medical Home Implementation, co-sponsorship of a statewide medical home work group looking at issues in Maryland, creating more opportunities for parental input at the system level, and production of the *Extreme Medical Home Makeover* training series for pediatric practices.
- As a result of the enhanced partnerships with state agencies, providers, and other advocacy groups developed through the grant project, PPMD is taking the lead on creating a broad statewide Children and Youth with Special Health Care Needs Consortium. The Grantee is continuing and expanding activities begun under this grant as part of another 3-year Family to Family grant funded by the Maternal and Child Health Bureau.

Lessons Learned and Recommendations

- Involving stakeholders from the beginning and conducting outreach in communities are essential components for building a family-to-family health care information and education center. Funds and other resources are also required.
- Because of the complexity of the health care system for children with disabilities and of insurance coverage issues in general, family educators required extensive training and mentoring in order to gain the expertise needed to support other families. Active mentoring is essential for parents conducting outreach with unfamiliar communities.
- The State and the federal government should increase access to and the availability of services through public programs for CSHCN, and a comprehensive range of services should be available statewide.

- Medicaid needs to be expanded to cover children with disabilities whose family incomes are above the Federal Poverty Level. States should fully implement the portions of the Family Opportunity Act that permit families of children with disabilities to buy in to Medicaid.

Products

- PPMD staff developed a video describing FHIC services, which can be played in the waiting room of clinics and at health fairs, conferences, and trainings. They also introduced health care topics into several special education workshops in order to expand outreach, especially to minority communities (using school partners as translators).
- PPMD staff worked with the Department of Health and Mental Hygiene (DHMH) to create a series of brochures on public insurance programs, which are being distributed to parents and partner organizations. The series is also available on the DHMH website.
- PPMD staff worked with Maryland's Medicaid agency to develop a series of brochures for parents explaining Medicaid services.
- Project staff created the workshop *Show Me the Money*, to assist families in finding ways to finance care for children, and an interactive workshop called *Managing the Maze*, to teach families how to organize medical records for CYSHCN to improve quality of care. Other workshops developed through the grant include the following:
 - *Finding Community Resources*, which addresses the specific needs of the participants and matches those needs to local resources.
 - *Choosing a Health Care Plan*, which offers practical step-by-step information to help families of children with disabilities and special health care needs sort through their health care plan options.
 - *Getting Needed Services from Your Managed Care Plan*, which explains how managed care health plans work, and takes participants through the steps of referrals, authorizations, and other service barriers.
 - *Appealing Insurance Denials* covers the appeal process available to families and teaches strategies that can make appeals successful.

All materials and resources, which are an integral part of PPMD outreach and information dissemination to both parents and providers, will be made available on the website (<http://www.ppm.org/index.asp>). Workshops are presented throughout the State and are provided free of charge to parents of children with disabilities. Fees for professionals vary by workshop.

Montana

Primary Purpose

The grant's primary purpose was to develop a Family to Family Health Care Information and Education Center to (1) increase the capacity of the Parent Training and Information Center's existing infrastructure in order to provide health care information and education to parents of children with special health care needs (CSHCN) that will enable the children to live in the most integrated setting with appropriate supports, (2) increase collaboration among public and private entities to ensure that families with CSHCN receive accurate and timely information from their peers, (3) strengthen statewide support of CSHCN by increasing the presence of family advocates within the health care system, and (4) facilitate the sustainability of family-to-family activities by providing a means for ongoing education and support for families with CSHCN.

The grant was awarded to Parents, Let's Unite for Kids (PLUK), the State's Parent Training and Information Center, which parents of CSHCN in Montana formed in 1984 to provide information, support, training, and assistance to ensure that their children have access to high-quality educational, medical, and rehabilitation services. PLUK uses a statewide team of well-trained volunteers who provide support and skill building for positive interactions with the education system (<http://www.pluk.org>).

Results

- The grant enabled PLUK to become a Family to Family Health Care Information and Education Center by expanding its services to include providing information and assistance related to health care issues for families of CSHCN. All of PLUK's staff and parent training and publications now include information about health care for CSHCN.
- In the final year of the grant, staff and volunteers handled nearly 10,000 direct contacts with families, professionals, and individuals and provided individual assistance to more than 2,000 families. They also developed a CD library of materials to cost-effectively provide a large amount of information to families.
- PLUK developed and implemented an outreach plan to provide training and to disseminate information throughout the State, including its most remote regions and Indian Reservations. Outreach activities helped to increase awareness about the services available to families of CSHCN and how to obtain them; outreach has been among the most successful activities begun by the project and will be continued and expanded.
- PLUK staff and/or peer trainers trained volunteer parents throughout the State to be CSHCN advisors. The trainings were provided in-person locally and on a statewide basis through videoconferencing and Internet streaming. Training announcements are made in the bimonthly newsletter and by mail and e-mail.
- The grant facilitated the development of a statewide, self-sustaining peer network project using the associate board concept. Seventeen associate boards—including Native

American—with advisory board functions were established and moved beyond their initial peer support role to look at additional needs in their communities.

- PLUK established a contractual relationship with Montana’s Children’s Special Health Services. Initial collaborative activities have been minor—developing publications for parents—but they are the first steps in an ongoing relationship that will increase the ability of the Family to Family Health Care Information and Education Center to provide information and referral services to families.

Lessons Learned and Recommendations

- Children’s disabilities and health care needs do not occur in a vacuum. They affect many other areas, such as mental health and education, and the needs of families of CSHCN also span many areas, including housing, employment, and public benefits. Although resources to meet these children’s and families’ needs are inadequate, the real challenge to increasing access to and the availability of services for CSHCN is bringing state agencies together to address issues strategically and share resources. No organizations or agencies have all the resources and expertise needed to address issues in all of these areas for families statewide. Collaboration is key to success, and working together has much more impact than working individually.
- The peer network of associate boards is perhaps the most powerful tool for giving communities a voice and for leveraging the network to address issues strategically.

Products

- PLUK STAFF developed a *Health Care Resources Handbook* and *Health Care Transition Handbook* in collaboration with Montana’s Children’s Special Health Services for use by PLUK’s Family Support Consultants who provide individual assistance to families. The Handbooks are in the final stages of preparation and will be printed soon.
- PLUK staff also contributed to the development of *Montana Parent’s Handbook on Transition: Adult Living* to answer questions that parents frequently ask about the transition process from childhood to adulthood.

Nevada

Primary Purpose

The grant's primary purpose was to develop a Family to Family Health Care Information and Education Center (FHIC) to (1) increase the understanding and use of appropriate health care resources for children and youth with special health care needs (CYSHCN), and (2) promote family-centered and self-directed health care services and supports.

The grant was awarded to Family TIES of Nevada, Inc., a consumer-run organization whose mission is to provide training, information, emotional support, and advocacy to increase the hope, confidence, and independence of people of all ages with disabilities or chronic health conditions. Family TIES is an affiliate of Family Voices, a national organization that speaks on behalf of CYSHCN and is the designated state Parent to Parent organization.

Results

- The Grantee expanded its mission by establishing a Family to Family Health Care Information and Education Center, which is run by its staff and volunteers.
- Grant staff established a Family TIES website and an online Resource Directory, which is a searchable database of resources and services for people with disabilities (available at <http://www.familytiesnv.org>). The Resource Directory will be continually updated. Grant staff also developed training materials specific to the needs of families of CYSHCN.
- With additional funding from a Champions for Progress Incentive Award, grant staff created a training curriculum and hosted a 1-day workshop (Nevada Youth Health Care Transition Training) to educate youth, family members, and medical professionals about transitioning youth with special health care needs from pediatric to adult services. The workshop was adapted to be available on the Family TIES website, and other online training options will be added.
- Grant staff developed a series of conference calls to help educate families and providers. Topics included state health care financing for CYSHCN, Medicaid services, advocating for private insurance coverage, Part C early intervention regulations, and caring for caregivers. The last topic was recorded and uploaded on the website. The 1-hour call-in format is a successful method for providing information, and Family TIES plans to continue offering the calls and to expand the topics covered.
- Grant staff developed another workshop (How to Toot Your Own Horn) to help similar organizations serving families of CYSHCN to identify practical strategies to promote their organization and services through the media. The training was presented originally at the Family Voices National Conference in Washington, DC, in 2006 and was revised for a 2007 family leadership workshop in Honolulu, Hawaii.

Elements of the training have been and will continue to be used in the Nevada Partners in Policymaking training. Grant staff also developed a training module and corresponding

study guide, entitled *Building Connections Between Families, Schools and Communities*, to help families of CYSHCN learn how to create a supportive community for themselves and their children. This training is available on DVD.

- To address the needs of the State's growing Hispanic population, grant staff assisted with the ongoing operations of Hidden Miracles, a support group in Las Vegas for Hispanic families who have CYSHCN. They translated Family TIES' newsletters and handouts into Spanish, offered a number of the conference calls in Spanish, disseminated existing materials and information in Spanish, and referred Hispanic families to community resources.
- The Grantee received additional funding for the FHIC through the Human Resources Services Agency, which will enable a more comprehensive evaluation of the FHIC to be undertaken.

Lessons Learned and Recommendations

- A significant number of the State's CYSHCN are uninsured and underinsured—higher than the national average. A Medicaid buy-in option would help working families who have private insurance but whose coverage does not meet their child's health care needs. (The legislature failed to enact a Medicaid buy-in option in the last session.)
- Partnering with the other Systems Change Grantees in Nevada was very beneficial. By working together, each project was strengthened. Additionally, Grantees forged new partnerships with state agencies that have a shared interest in CYSHCN, which prevented a duplication of systems change efforts.

Products

Outreach Materials

Grant staff produced an organizational brochure and developed a website to promote Family TIES and the Family to Family Health Care Information and Education Center. They also produced a newsletter and a flyer promoting the online Resource Directory. Issues of the newsletter are archived on the website to be used as handouts.

Educational Materials

Grant staff developed several courses for professionals and families of CYSHCN, some of which are now available on the Family TIES website. They also developed an online Resource Directory that contains information about resources and training opportunities available to families of CYSHCN.

New Jersey

Primary Purpose

The grant's primary purpose was to develop a Family to Family Health Information and Resource Center (FHIC), whose objective is to provide the information and support that families of children and youth with special health care needs (CYSHCN) must have to partner effectively in decision making to ensure the availability of appropriate community-based systems of services.

The grant was awarded to the Statewide Parent Advocacy Network, Inc. (SPAN), a family education and advocacy agency in New Jersey. SPAN's foremost commitment is to children and families with the greatest need due to disability; poverty; discrimination based on race, sex, language, immigrant, or homeless status; involvement in the foster care, child welfare, or juvenile justice systems; geographic location; or other special circumstances.

Results

- SPAN established a Family to Family Health Information and Resource Center, which allowed its staff and volunteer Resource Parents to develop partnerships with hospitals, clinics, mental health facilities, family support organizations, immigrant networks, and other organizations, thereby facilitating the dissemination of information and support for families statewide.
- Project staff and volunteers facilitated 24 focus groups with families of CYSHCN, as well as with youth and professionals, to gather information to determine best approaches to reach diverse families of CYSHCN, and to shape project activities and bring about systems change. For example, feedback about service quality and gaps in services was shared with the New Jersey Departments of Children and Families, Health, and Human Services, and these agencies are using the information to improve quality and fill gaps.
- During the grant period, staff and volunteers provided information and technical assistance via phone and e-mail to 102,700 families and professionals, as well as in person to more than 4,200 families. An additional 144,095 families and professionals obtained information from the Family to Family section of SPAN's website, including 29,390 who accessed the website's Spanish language section.
- Project staff built families' leadership capacity by facilitating a number of parent leadership trainings and developing a Statewide Family Council (15 of the 20 parents are African-American or Latino) to advise the Commissioner of the Department of Children and Families on family support, child welfare, and child behavioral health services. Staff also helped to develop a Kids as Self-Advocates chapter, which brings the views of youth with special health care needs into the policy-making processes that affect their lives.
- About 400 parent volunteers participated in trainings in how to provide emotional support and/or information to other parents and families of CYSHCN.

- During a full-day workshop, project staff trained 340 medical students who were in their third-year pediatric rotation at the State's medical school; each medical student also spent an evening with a family of a child with special health care needs. The training focused on the importance of providing coordinated, ongoing, comprehensive care within a "medical home" and on strategies to effectively serve CYSHCN.
- The Family to Family Health Information and Resource Center is fully operational, and families have access to support through the FHIC main office and 15 satellite offices. The offices are located in hospitals, mental health agencies, community-based organizations, Special Child Health Services (Title V) Case Management Units, and other sites, which are staffed by employees and/or trained volunteers in different regions of the State. Since the grant ended, the FHIC is funded through a grant from the Federal Maternal Child Health Bureau and the New Jersey Department of Health and Senior Services' Title V Program.
- Project staff gathered information from families to share with the legislature, which helped bring about key legislative changes: (1) significant increases in funding for family support and health services; (2) a new State Children's Health Insurance Program (SCHIP) buy-in, even for families with incomes above 350 percent of the federal poverty level (FPL); (3) wraparound prescription coverage for children dually eligible for Medicaid and Medicare; (4) eliminating proposed Medicaid copays; (5) increasing Medicaid's specialty care reimbursement rates; (6) increasing funding for early intervention; (7) maintaining early intervention services at no cost to families at up to 350 percent of the FPL; (8) requiring cultural competence training for health care professionals; and (9) requiring the State to apply for Medicaid waivers for children's services.

Lessons Learned and Recommendations

- Prioritizing the development of leadership skills for parents and families of CYSHCN is a key strategy in bringing about systems change. Training develops parent leadership, first to advocate for their own child, then to support and advocate for other children and families, and then to participate in systems change activities.
- When beginning systems change activities, involving people who are directly affected—particularly those with least access to services and supports (e.g., people of color, low-income, non-English speaking)—it is essential to identify what is and is not working and why; to determine how to address problems and barriers; and to develop, implement, and evaluate improvements.
- Using focus groups is an effective strategy to identify the needs and strengths of families from diverse backgrounds, and to develop supports and services to address those needs and build on those strengths. Also, using cultural brokers to work with families from diverse cultures and creating partnerships with community-based, immigrant, and other organizations can maximize reach and effectiveness.

- To correct the continued institutional bias in Medicaid and state policies, the provision of home and community-based services should be mandatory, and waivers should be required for institutional services.

Products

Outreach Materials

Grant staff developed outreach materials targeted to families of CYSHCN in English, Spanish, Chinese, and Haitian-Creole. Additional outreach materials were developed in collaboration with the State's Early Hearing Detection project for families of children with deafness/hearing loss. They also developed population-specific outreach materials for Latino organizations to help them identify, refer, and support families of CYSHCN.

Educational Materials

- Project staff and volunteers developed multiple materials for families of CYSHCN and professionals, including an interactive *Transition to Adult Life* CD-ROM of resources for youth; transition resources for health practitioners; a CD-ROM of resources on including young children with special health care needs in early childhood programs; an information packet in English and Spanish of resources for families of children who are deaf or hard of hearing, and for professionals who provide services to this population (a brochure, parent information packet, and CD); and a Medicaid managed care fact sheet series.
- Project staff also developed various training curricula for early intervention providers, service coordinators, and families; curricula for early intervention parent leadership development and for Statewide Family Council leadership development; curricula on family involvement in systems change; intensive health advocacy curriculum; an online training course for Child Care Resource and Referral agencies to inform them of the rights of young CSHCN and their families, and about resources to support and strategies to work more effectively with those families; and a workshop on the child behavioral health system and services in New Jersey.

Technical Materials

- Grant staff developed a guide for school districts to help them secure additional funds to educate students with significant needs in their communities and in more inclusive settings.
- Grant staff worked with the chair of the state Senate Health Committee to develop a user-friendly one-page application for SCHIP.

Reports

Grant staff developed a report based on the focus group findings on barriers to health care access for CYSHCN and also on family support needs. The findings were shared with the state Departments of Health, Human Services, and Children and Families, as well as with the Association for Children of New Jersey, the New Jersey Council on Developmental

Disabilities, the New Jersey Immigration Policy Network, the Governor's office, and numerous legislators. The report can be obtained by e-mailing Diana.autin@spannj.org.

South Dakota

Primary Purpose

The grant's primary purpose was to expand the capabilities of the State's Parent Training and Information Center by creating a Family to Family Health Care Information and Education Center (FHIC) that will (1) provide information, referrals, and education about health care and home and community-based services statewide to those caring for children with special health care needs (CSHCN); (2) connect those caring for CSHCN with local training opportunities, information, services, advocacy, and other parents of CSHCN; (3) provide culturally competent training and information for the Native American and Spanish-speaking families of CSHCN; and (4) collaborate with existing FHICs to promote the philosophy of individualized, family-directed support.

The grant was awarded to South Dakota Parent Connection, Inc. (SDPC), which is the State's only Parent Training and Information Center.

Results

- The Grantee established the Family to Family Health Care Information and Education Center, which will operate within SDPC. The FHIC staff established partnerships and working relationships with health care providers, the two major hospital systems in South Dakota, and state agencies. The establishment of the FHIC expanded SDPC's focus to include the provision of information, training, and other resources in the area of health care for CHSCN. SDPC staff provided information and assistance to families in the following areas: Medical Home information (2,438 requests), Mental Health (879 requests), Respite Care (424 requests), Transition (556 requests), and referrals to community resources (3,543 requests).
- Grant staff developed training materials for families and professionals and presented 275 workshops attended by 2,390 parents and 3,372 professionals, approximately 11 percent of whom were minorities. They also promoted training and disseminated information through newsletters and websites. When families needed to travel out of state for health or medical services, grant staff were able to link them with families in those states to provide support and help them connect with services.
- Grant staff provided training for social workers who work with families caring for CSHCN on the following topics: Navigating the Health Care Maze, Patients'/Parents' Bill of Rights, Health Care Resources in South Dakota, and Child Abuse and Reporting.
- SDPC staff, in collaboration with other agencies, developed a Folder of Information and Life Experiences (FILE), a record-keeping system for families of children with disabilities and CSHCN, and mailed or distributed 500 copies to assist families in maintaining their children's educational and medical records.
- Grant staff developed a database of more than 400 parents and families of CSHCN who are interested in working with other families, and conducted training using several

formats, including small group settings, one-on-one, and self-learning using a CD either in the SDPC office or at home. All training materials and information resources developed by the Grantee are available to families and professionals in electronic format on the SDPC website (<http://www.sdparent.org/>), which contains an FHIC web page.

- SDPC-FHIC staff developed Parent Tips and Fact Sheets on several topics, including *Grandparenting, Working with Doctors, Autism, Fatherhood, Attention Deficit Disorder/Hyperactive Disorder, Stress Reduction, and Mental Health*. They also developed a *Health Care Resource Guide* that will be distributed through clinics and community health centers and on the SDPC website.

Lessons Learned and Recommendations

- Because families caring for CSHCN have limited time, it is important to provide opportunities for education and training at convenient times and places. Using technology and web-based activities makes it possible to reach families who cannot attend in-person meetings.
- Enacting the Family Opportunity Act in South Dakota would help families whose income fluctuates or is slightly above the income guidelines for SCHIP and Medicaid eligibility, by establishing a sliding scale.

Products

Outreach Materials

Grant staff produced a brochure with basic information on services and supports for families of CSHCN and professionals who work with families, which is available on the SDPC website.

Educational Materials

Grant staff developed workshop curricula for SDPC staff and volunteer Parent Trainers to work with families and health care professionals. The curricula included the following topics: *Navigating the Health Care Maze, Patients'/Parents' Bill of Rights, Health Care Resources in South Dakota, and Child Abuse and Reporting*. The workshop handouts are available in English and Spanish, and interpreters are available for Hispanic families.

Technical Materials

SDPC staff served on the revisions and reprint committee for the Folder of Information and Life Experiences, a family record-keeping system. Their participation ensured that health care information relevant for families of CSHCN was included in the FILE. The system has 10 folders to help families sort and find papers related to the following: Family Records, Developmental History, Medical, Therapies, Individual Family Service Plan/Individual Education Plan, Letters/Contact Info, Evaluations/Consents, Respite Care/Child Care, Transition, and Legal & Life Planning.

Wisconsin

Primary Purpose

The grant's primary purpose was to develop a training curriculum and sustainable methods for delivering it so that parents of children with disabilities and special health care needs (CDSHCN), including those in under-represented segments of the community, can be knowledgeable and effective navigators of their child's system of care. Other grant objectives were to increase coordination among existing, state-funded information and assistance activities, to increase the availability of health and community resources for CDSHCN, and to support parent involvement to shape these resources and develop the infrastructure for a sustainable Family to Family Health Care Information and Education Center (FHIC).

The grant was awarded to Family Voices of Wisconsin (hereafter, Family Voices), a nonprofit organization that is part of the national Family Voices network, which promotes a system of comprehensive health and community supports based on fundamental principles that ensure the health and well-being of CDSHCN and their families. The role of Family Voices is to advocate for the inclusion of these principles in the design, implementation, and delivery of services and supports throughout Wisconsin (see <http://www.wfv.org/fv/aboutfwi.html>).

Results

- Family Voices convened a statewide planning group over a period of 18 months to explore how Information, Assistance and Advocacy (IA&A) services could be provided most effectively to people with disabilities. The group inventoried the State's current capacity to serve individuals, its database technology, and options for sharing databases. The inventory was formatted into an easily understandable brochure and was also formatted for easy navigation on the Family Voices website.
- The Grantee developed a logic model, a mission statement, and guiding principles to inform the organizational structure of the FHIC, which is administered by Family Voices. The FHIC now has two co-directors and a training and outreach coordinator and has developed a brochure, listserv, newsletter, and website. Parent trainers are paid as consultants based on the number of trainings they are able to provide (\$250 per session). Each trainer is expected to provide the training at least twice annually in his or her region of the State.

Additional funding for the FHIC has been secured through a grant from the federal Maternal and Child Health Bureau and through a contractual arrangement with the Title V program to build and support a statewide network of parents who can present their views on policy, quality improvement, and program development. This contract will complement the activities of the CMS grant and sustain the parent training network beginning in 2009. Family Voices is also meeting with several counties and the United Way to discuss future work together, and continues to seek opportunities and funding to broaden its base and to provide greater organizational stability.

- To increase the availability of information to families to help them obtain health and community-based services and supports for CDSHCN, grant staff devised two strategies: a five-part (10-hour) face-to-face training and an e-mail listserv. The training modules provide information on the following topics: Parents and Partners on a Journey, Public Support Systems, Private Insurance and Your Doctor, Medicaid, and Advocating for Change. Extensive materials were compiled or developed for each module to support the presentations. Training is presented in single- or multi-session formats depending on the audience and collaborating partners. Although the training has been designed for families, county agencies increasingly are requesting portions of it for their staff involved with early intervention, social work, and children's long-term support.

Parents from across the State were recruited to participate in a train-the-trainers program, resulting in a statewide network of 25 parent trainers who are supported to provide the face-to-face training to families and providers. The parent training network meets bimonthly via conference call and annually for a 2-day event. The conference calls provide additional content information on elements of the training and the annual meeting enables the parent trainers to refresh their skills, to acquire more information, and to network with other parent trainers. Individual calls are also used to provide one-to-one support to trainers on a personal level.

Grant staff paid particular attention to the recruitment of minority parents, and unique versions of the curriculum were developed for Native American families in collaboration with the Great Lakes Intertribal Council, for African American families in collaboration with FACETS, and for Latino families in collaboration with Family Support 360. The curriculum was also translated into Spanish. As of July 2008, more than 500 parents and providers had participated in training offered in 38 locations around the State. An evaluation of the trainings demonstrated very high participant satisfaction.

- Family Voices staff participated in Department of Health and Family Services work groups that developed recommendations for (1) policy changes in the Family Support Program "First Come First Serve" to require all counties to develop policies to serve urgent or crisis situations and allocate funding accordingly; and (2) the allocation of new funding to address waiting lists, urgent needs, and youth in transition; and drafted an easily understandable document explaining the shift from identifying services to outcomes-based planning with families.
- In collaboration with the Survival Coalition of Wisconsin, Family Voices developed a series of proposals for the FY 2007–FY 2009 biennial state budget that included funding to address waiting lists, an investment in an infrastructure to provide IA&A services for CDSHCN, and funding to pilot principles of managed care for CDSHCN. (Materials outlining these proposals can be found at <http://www.wfv.org/fv/statebudget.html>.) This effort resulted in the inclusion of \$4.7 million to address waiting lists for Children's Long-Term Supports in Year 1 and \$4.8 million in Year 2, which was the first significant increase in funding for children's long-term supports in 12 years.

Lessons Learned and Recommendations

- Parents are a critical partner in the “workforce” that supports CDSHCN yet often do not have access to the high-quality training and information they need to support their child/young adult’s needs and to be effective advocates and allies with the professionals they work with. This training, support, and leadership development must be an integral component of the infrastructure of state systems.
- The development of a dedicated and well-informed parent trainer network requires a significant level of support and nurturing.
- Overall, the parent trainers expressed a high degree of preference for face-to-face trainings. They found the bimonthly conference calls less effective because of the frequency of the calls and personal scheduling issues. Many of the parent trainers stressed that a limited number of conference calls each year—two to four times—would be useful for planning events or to provide critical updates on programmatic or other issues.
- The Department of Health and Family Services has made a commitment to end waiting lists for community-based services and supports for adults of all ages with disabilities, but no such commitment has been made to children and their families. As Wisconsin continues to expand Aging and Disability Resource Centers, the disparity between resources dedicated to adults with disabilities and CDSHCN becomes more apparent. The need for a single point of entry coupled with high-quality information remains an essential but unrealized element of the children’s system. Family Voices will attempt to engage government, advocacy, and family partners to again make the case for a well-funded initiative in this area.
- Medicaid policy focuses on the individual receiving services, which leads to a lack of flexibility in meeting the needs of CDSHCN living with their families, particularly to support the health of family members and their ability to care for their child at home. Medicaid policy should allow families with children under 18 with significant disabilities to be reimbursed for personal care and other expenses specific to caring for their child.

Products

Outreach and Educational Materials

- The Grantee, in collaboration with Disability Rights Wisconsin, the Waisman Center, and the Wisconsin CDSHCN network, produced the booklet *Information, Assistance & Advocacy Resources for People with Disabilities in Wisconsin*, which is an inventory of IA&A agencies with a statewide or multiregional presence whose primary missions are to provide information, assistance, and/or advocacy to CDSHCN and their families and to adults with disabilities. The booklet was produced in print and electronic media, and is also available at <http://www.wfv.org/fv/ir/>.
- Family Voices developed a five-module curriculum for parents in English and Spanish: Did You Know? Now You Know! The modules provide a comprehensive, fundamental

overview of health care access, coverage, and community supports for CDSHCN from birth through young adulthood. The training can be offered in a variety of time formats (e.g., two half-day sessions or five 2-hour evening sessions), and Family Voices can customize the training to meet local needs.

- Additional resources developed for the Family Voices website cover information on policy issues and on communicating with your legislator, on accessing and using Medicaid and private insurance (<http://www.wfv.org/fv/docs.html>), and include a listing of statewide resources by topic (<http://www.wfv.org/fv/topic.html>).

Reports

Grant staff produced a report for Wisconsin's Title V program—*Strategies to Increase Minority Parent Participation in Decision Making Roles on Behalf of CDSHCN*—to assist in engaging minority families.