

FAMILY VOICES[®]

VOICES FROM HOME

2006



*A report on activities of the Family Voices
network of family and youth leaders*

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Family Voices, Inc. • 2340 Alamo SE, Ste 102 • Albuquerque, NM • 87106
(888)835-5669 • kidshealth@familyvoices.org • www.familyvoices.org

INTRODUCTION

The Family Voices network of family and youth leaders makes a daily difference in the lives of families of children and youth with special health care needs (CYSHCN). Whether guiding a parent in applying for Medicaid, sharing experiences with a peer, discussing the implications of policies with their state Title V Program, or providing real life stories in testimony before a state legislature or Congress, the work of the FV network improves the quality of life for CYSHCN, a population of more than 9 million in the US.



BACKGROUND

Family Voices was founded in 1992 as a national grassroots organization of families and friends concerned with national health care reform. As the network developed, it was clear that a connected group of family and youth leaders filled an enormous need for information, expertise, partnership and support not only for family and youth leaders but for the professionals who care for CYSHCN.

Today, Family Voices is represented by Network Members in almost every state, as well as the District of Columbia and Puerto Rico and includes a growing youth network, Kids As Self Advocates (KASA). State Family Voices organizations are organized into the HRSA regions led by elected Regional Coordinators who

connect and mentor the leaders in their regions. Some Family Voices state activities are volunteer efforts while many operate with funding, through grants directly to their family organization or to a host organization. Regardless of their structure, Family Voices Network Members believe in a common set of principles:

- * **Every child and youth deserve quality primary and specialty health care** that is affordable and within geographic reach.
- * **Families are the core** of this nation's health system, their children's most important health providers and caregivers.
- * **Quality health care is family-centered, community-based, coordinated, and culturally competent.**
- * Family-centered health benefits and services are flexible, and **guided by what children and youth need.**
- * **Strong family-professional partnerships** improve decision-making, enhance outcomes, and assure quality.
- * Families practice **cost-effectiveness** and expect the same from our health systems and services.



Dedicated family and youth leaders are the heart and soul of Family Voices. Voices from Home 2006, compiled from information submitted by the network, is a glimpse into some of the extraordinary activities undertaken by these youth and family leaders in their tireless efforts to improve systems of care for CYSHCN.

NATIONAL ACTIVITIES

Family Voices supports its network of family and youth leaders and engages in national-level projects and activities. The support provided to the network through this national-level work includes mentorship, information and technical assistance, critical insight into national policy, up-to-date news on research, and opportunities to partner with professional organizations and other family organizations. In turn, the network provides national activities and projects with valuable insight and information from the grassroots level. National activities include:

NATIONAL CENTER FOR FAMILY/PROFESSIONAL PARTNERSHIPS

One of six national centers funded by MCHB to address the six performance outcomes for CYSHCN, the National Center on Family/Professional Partnerships for Children and Youth with Special Health Care Needs (NCFPP) is focused on helping families of CYSHCN to partner in decision-making at all levels. The goals of the NCFPP are to:

1. Increase leadership capacity and promote family-centered care by providing technical assistance to Family-to-Family Health Information Centers (F2F2F HICs) and communities of learners;
2. Promote knowledge about and opportunities for family/youth/professional partnerships in health care policies and practices;
3. Contribute to the understanding and measurement of family-centered, culturally competent care, family/professional partnerships and other outcomes.

The goals of the NCFPP are undertaken through: technical assistance and mentoring, meetings and training, communication facilitation (listservs, conference calls, websites, materials), collaborations with other national centers and a wide variety of other partners, facilitation of partnership opportunities, and development of evidence-based information.

IMPACT

A project, funded by MCHB, that provides information about maternal and child health policies and practices for all children and youth through Bright Futures materials and promotes active communication between families and their professional partners.

FAMILY MATTERS

A research project, funded by CDC, that investigates what families of children with disabilities know about promoting health and wellness and identifies effective strategies for developing healthy lifestyles for CYSHCN.

DATA RESOURCE CENTER

A partnership with CAHMI, funded through a contract with Oregon Health Sciences University, that assists in the development and promotion of an interactive website providing user friendly access to national surveys about the health of children and youth.

KIDS AS SELF ADVOCATES

See page 54.



LEGISLATIVE ACTION CENTER

A web-based (www.familyvoices.org) resource, funded by private funds and donations, that provides current news on legislation and an easy way for families to contact their elected officials to express their views on proposed legislation.

Family Voices of Alabama



SUSAN COLBURN

1520 Hallwood Lane
Montgomery, AL 36117
Fax: (334) 613-3553

❖ (334) 613-2284
(800) 846-3697 (AL)

❖ susan.colburn@
rehab.alabama.gov

GERALD OVESON

1050 Government Street
Mobile, AL 36604-2404
Fax: (251) 438-1609

❖ (251) 438-1609

❖ govesson@mchsi.com



WORKING TOGETHER FOR CYSHCN:

In 2006, Family Voices of Alabama increased their involvement in many of the emergency preparedness efforts in AL, both at the local and state level. This included serving on a Department of Public Health task force focused on Special Populations and another workgroup focused on meeting the needs of children who come to the newly created network of Medical Needs Shelters, as well as helping to develop a plan for accessible transportation in the case of a mandatory evacuation from the coast.

Family Voices of Alabama (FV of AL) provides assistance to families of CYSHCN in a variety of ways, including individualized information and support, trainings, and information sharing at conferences and through various newsletters and listservs. They encourage families to develop individual partnerships with their children's care providers, and to look for opportunities to impact systems change by working collaboratively with the many agencies in the state that care about services for children and youth with special needs. FV of AL does not receive direct funding for these activities, but is supported through in-kind services provided by such organizations as the Children's Rehabilitation Service (Title V CSHCN Program).

2006 HIGHLIGHT: *Focus on Underserved Populations*

Family Voices of AL led a grassroots effort to increase state funding for their Title V program for CSHCN by coordinating and funding a statewide letter writing campaign from families to state legislators. This resulted in the agency receiving the largest one-time increase in funds it has received and prevented the discontinuation of important services to children and families.

BUILDING PARTNERSHIPS: *Families and 2010 Performance Measures*

FV of AL, in partnership with the AL Title V CSHCN program, continues to provide a mechanism to financially support family involvement in each of the six workgroups for the national performance measures for CSHCN. These workgroups are made up of partners from many agencies across the state all with an interest in CSHCN. Highlights include:

- ☑ **Screening:** Serving on newly appointed State Newborn Screening Advisory Committee
- ☑ **Transition:** Serving on steering committee to develop and implement Transition Expo events being held in communities across AL
- ☑ **Family/Professional Partnerships:** Working with new partners and expanding opportunities for family involvement in Emergency Preparedness efforts
- ☑ **Adequate Insurance/Medical Home:** Member of Covering AL's Kids and Families Coalition

"At first, the world of disability is so overwhelming. Thank you for taking the time to help me learn about agencies in our state that I never even knew existed. Knowing that there is help to pay for some of the medical services my child needs has helped me to relax and lets us enjoy just being a family."

- a parent

Strong family-professional partnerships
improve decision-making, enhance outcomes,
and assure quality.

-a Family Voices Principle

Family Voices of Alaska

www.stonesoupgroup.org



JAYSON SMART

N18751 Sarchief Loop
Eagle River, AK 99577

❖ Tel: (907) 694-7661

❖ jsmart66@gmail.com



BUILDING CAPACITY TO SERVE FAMILIES:

Stone Soup Group, a statewide collaboration of families and friends concerned with the health and well-being of Alaskan children with special health care needs, was awarded the State Parent Training and Information (PTI) Center grant in 2006. This grant has enabled them to serve families in a more comprehensive manner, bringing together such resources as parent-to-parent support, family training, and advocacy. The PTI grant expands their ability to address special education system issues, in addition to health-related advocacy.



Family Voices of Alaska (FV AK), a project of Stone Soup Group, provides information and support to families as they navigate health care systems in Alaska as well as to the professionals who serve such families. This is done through:

- * individualized support
- * support groups
- * parent matching
- * training
- * focus groups
- * conferences
- * lending library
- * videos
- * resource guides
- * care notebook
- * surveys
- * listservs
- * newsletters
- * website
- * topical calls

Funding to support these activities is provided by Alaska Department of Health and Social Services, CMS (F2F grant), Real Choice Systems Change Grant, Administration on Developmental Disabilities, SAMHSA, and Rueben E. Crossett Endowed Alaskan Fund.

2006 HIGHLIGHT: Oral Health

At the end of 2006, Stone Soup Group was awarded a small grant from the Association of State and Territorial Dental Directors (ASTDD) to facilitate a statewide forum on oral health for CSHCN. This forum was coordinated in partnership with the Alaska State Dental Officer, and Women's, Children's and Family Health (WCFH) agency. The forum was well attended by professionals and parents alike. The following message was sent several weeks following the forum to update the forum planners on progress and outcomes from the forum (as reported by the State CSHCN program):

"The oral health forum made participating practitioners realize they need to do a lot more for CSHCN. After the Dental Director at a local hospital brought it up with the dental staff, about half of them volunteered to meet during their lunch break to brainstorm ideas. Now they are establishing a protocol for CSHCN. The children will be assigned to a team who will follow them over time. The dental teams are also planning a CSHCN clinic where they can implement their ideas. I think it will be a few months before they can try a pilot clinic for CSHCN, but they are really excited about getting something in place."

- a professional

This is a significant outcome for Alaska's children who are seeking oral health care, and something of which Stone Soup Group is very proud.

Family Voices of Arizona

www.raisingpecialkids.org



WENDY BENZ

2400 N. Central Ave, Ste. 200
Phoenix, AZ 85004-9802
Fax: (602) 242-4306

❖ (602) 242-4366 x.204
(800) 237-2007 (AZ)
(480) 329-0404

❖ wendyb@
raisingpecialkids.org

JUDIE WALKER

150 N. 18th Ave Suite 330
Phoenix, AZ 85007-3243
Fax: 602) 542-2589

❖ (602) 364-1477

❖ jwalker@azdhs.gov



BUILDING PARTNERSHIPS:

Families and Providers

Raising Special Kids teaches future health care providers the value of a strong family-professional partnership through the Family and Community Medicine Program. Last year, 96 physicians in pediatric and family practice residency programs completed this program. Workshops and seminars in family-centered care principles are also held for student nurses and dental students.

"This has been one of the best experiences in my residency training. All of my questions were answered...a couple of these experiences would be beneficial as opposed to just one."

- a physician in pediatric
residency

Family Voices of Arizona (FV of AZ) at Raising Special Kids Inc. provides assistance to families of CYSHCN in a many ways: direct support, conferences, focus groups, listservs, newsletters, support groups, parent matching, training, resource guides, web-based information, and surveys. Funding from several sources supports this effort, including CMS, AZ Division of Developmental Disabilities, US Department of Education, AZ Department of Health Services, and the AZ Department of Education. Staffs at FV of AZ have volunteered over 2,500 hours in providing assistance to families and professionals.

2006 HIGHLIGHT: *Focus on Training*

A key focus this year has been the development of a comprehensive training module for both families and professionals, An Overview of Arizona's Health Care Systems, providing insight into the complicated health care financing and service delivery systems for CYSHCN in AZ. Significant to this development is the packaging of this training module to reach different audiences, such as families in rural areas, agency staff, and others. This effort includes:

- * a staff-led 3-hour workshop,
- * a CD version using a 'train-the-trainer' model,
- * an online class offered via the Title V program's distance education system for families and professionals, and
- * downloadable fact sheets from the website.

The popularity of this training has spread, as evidenced by numerous state agencies and providers requesting this overview in order to provide staff and contractors with needed information to better assist families of CYSHCN.

WORKING TOGETHER FOR CYSHCN:

FV of AZ has worked with other partners to help prepare families for emergencies. Collaborations with the statewide independent living centers, state technology access program, county emergency planning offices, state Depts. of Health, Economic Security, Education, the Title V program, as well as families, medical providers, and first responders are developing:

- recommendations for schools to address CYSHCN in campus emergency plans,
- participation of CSHCN in state and county disaster drills,
- guidelines for including emergency plans and practice in IEPs,
- a podcast training for families of CYSHCN about emergency preparation at home and school, and
- trainings for first responders about people with disabilities & special needs.

Family Voices of Arkansas



RODNEY FARLEY

110 Louise Street
North Little Rock, AR 72118
Fax: (501) 371-3464

❖ (501) 753-3163

❖ refarley@juno.com



ADVOCACY IN ACTION:

In 2006, FV of AR:

- Distributed over 50,000 newsletters
- Engaged 375 individuals by listserv
- Informed over 1,700 families and professionals by participating in 124 meetings



BUILDING PARTNERSHIPS:

Families and Providers

FV of AR works with Project DOCC (Deliver of Chronic Care) to train families to be teaching faculty for pediatric residents.

"I am very impressed with the positive attitudes of the pediatric residents that I have met. I have been a visiting parent and have had a parent interview."

- a family participant in DOCC

Family Voices of Arkansas (FV of AR) advocates for CYSHCN through a variety of activities to promote the voice of families at both the state and federal level. With funding from Arkansas Title V Program, a Champions for Progress grant, stipends from Family Voices, and through 600 hours of time volunteered in 2006, Family Voices of Arkansas endeavors to provide information and assistance to families and professionals through: conferences, support groups, parent-matching, listservs, newsletters, and resource guides.

2006 HIGHLIGHT: *Summit for Political Candidates*

As a member of the Arkansas Disability Policy Consortium (ADPC), Family Voices of Arkansas participated in the Consortium's Summit for political candidates. All candidates for political office were invited, and those running for the office of Governor, Lt. Governor, and Congress participated in panel discussions. Families and people with disabilities were invited and encouraged to



Rodney Farley, Family Voices of AR
Network Member

attend the summit. The summit provided families the opportunity to ask questions of and share concerns with candidates from their districts. This year's summit included a surprise visit from Uncle Sam (a.k.a. Rodney) in order to draw attention to the issues facing CYSHCN. Rodney impressed candidates by handing them a fact sheet about CYSHCN in Arkansas asking them, **'Will YOU be a champion for disability rights?'**

WORKING TOGETHER FOR CYSHCN:

A sample of the many activities in which Family Voices of AR partnered with others in 2006:

- Worked with the Title V CSHCN Parent Advisory Council,
- Attended rallies on how upcoming legislation may impact people with disabilities,
- Informed families and legislators of Disability Awareness legislation,
- Held community meetings around the state to bring awareness about policies, services and programs
- Attended 2006 American Association of Maternal Child Health Programs (AMCHP) annual conference, and
- Met with state legislators on Capitol Hill

Family Voices of California

www.familyvoicesofca.org



JUNO DUENAS

2601 Mission St, Ste 206
San Francisco, CA 94110-3111
Fax: (415) 282-1226

❖ (415) 282-7494

❖ jduenas@supportforfamilies.org

LINDA SWAN

2601 Mission St, Ste 206
San Francisco, CA 94110-3111
Fax: (415) 282-1226

❖ (415) 282-7494

❖ lswan@supportforfamilies.org



ADVOCACY IN ACTION:

In 2006, FV of CA:

- ☑ Provided assistance to families & professionals over 12,000 times, on average, each quarter
- ☑ Logged over 5.1million web hits, on average, each quarter
- ☑ Participated in 832 meetings attended by over 8,000 family members & professionals



BUILDING LEADERSHIP:

FVCA is completing a **Leadership Manual** that will be used to train families to take on leadership rolls in their communities and advocate for CSHCN. Trainings will begin in May, 2007

Family Voices of California (FVCA) helps families of CYSHCN through a network of regional FVCA Council Member agencies, coordinated by **Family Voices at Support for Families** (San Francisco). These family-run member agencies are funded by a number of sources, including: First 5 County Commissions, US Department of Education, DDS Early Start, California Children’s Services, State Council on Developmental Disabilities, CA Department of Education, private and corporate foundation grants and others.



2006 HIGHLIGHT: Focus on Youth

FVCA started a Youth Advisory Council this past year for youth ages 14-24 yrs. Youth participants meet via conference call once a month and face-to-face 4 times per year. In these meetings to date they have developed ground rules for participation and identified projects to work on. Currently, the Youth Advisory Council is working on developing a survey of youth with special health care needs to obtain information about their needs and experiences of youth and the agencies serving them. **This is a dynamic group of young people who speak up and take very seriously their role on the Advisory Council!**

BUILDING PARTNERSHIPS: Families and Policy-Makers

FVCA held its annual Health Summit in the state capitol, bringing together families, legislators, advocates, and speakers from George Washington University, Families USA, legislators, advocates and state agency representatives. This was followed by a Legislative Day, during which families from across the state met with their state Senate and Assembly members to discuss CYSHCN and the impacts of budget and policy proposals on them.

WORKING TOGETHER FOR CYSHCN:

A sample of the many activities in which FVCA partnered with others in 2006:

- ☑ Developed a Parent Health Liaison (PHL) Network to identify and track emerging trends and issues for families
- ☑ Through the PHL network, developed a Hospital Discharge Questionnaire to ensure families have the information needed to care for their child at home upon discharge
- ☑ Collaborated with several child health advocacy groups to develop ‘Core Principles for CSHCN’, a set of guidelines for healthcare reform

Family Voices of Colorado

www.familyvoicesco.org



CHRISTY BLAKELY

69 Spyglass Dr
Littleton, CO 80123
Fax: (303) 973-4988

❖ (800) 881-8272
(303) 973-5780

❖ Christy957@comcast.net



ADVOCACY IN ACTION:

In 2006, FV Colorado:

- Distributed over 1,300 newsletters
- Informed, on average, about 300 individuals each quarter by listserv
- Participated in over 450 meetings attended by almost 5,170 families & professionals



BUILDING PARTNERSHIPS:

Families and Providers

Through the "Assuring Better Child Health and Development" (ABCD) Project, FV Colorado has worked with both Early Intervention (Part C) and Title V to implement a protocol for provider use of "Ages and Stages Questionnaire" (ASQ) during all well-baby visits.

"I thought it (ASQ) was going to take more time, but we are finding the tool can be used as a template to drive discussion with the parent and it saves time! We started doing it on all healthy screens!"

- a pediatrician

Family Voices of Colorado (FV Colorado) helps parents navigate the systems of care for their CYSHCN through their Family-to-Family Health Information Center, funded by CMS. They provide assistance through: direct support and communication, focus groups, trainings, conferences, family surveys, care notebook, resource guides, newsletters, listserv, video, and website. In addition to the F2F grant, these activities are supported with funding from Colorado Department of Public Health and Environment Health Care Program For Special Needs Children, Colorado Department of Education/Part C, and Smart Start Colorado.

2006 HIGHLIGHT: *Partnerships in Policy*

FV Colorado has been involved in three significant pieces of legislation slated for the 2007 legislative session:

- * Early Childhood - Coordination of private and public funding for EI services
- * Mental Health - Family Advocacy services to help families navigate Mental Health services
- * Medical Home - A mandate for a Medical Home approach to children's health care

FV Colorado has been instrumental in helping families speak up about these important issues. FV Colorado has helped families share their experiences and expertise with legislators by providing them with tip sheets and other guidance.

WORKING TOGETHER FOR CYSHCN:

FV Colorado collaborates with many organizations on legislative issues and helps to bring the family perspective to health care policy discussions in Colorado. They engage in weekly meetings with:

- Colorado Coalition for Health Initiatives
- Community Centered Boards
- Title V
- Children's Campaign
- ARC
- Children's Hospital
- Private Health Insurers



Family Voices of Connecticut



MOLLY COLE

190 White Rock Drive
P.O. Box 283
Windsor, CT 06095

❖ (860) 571-6855

❖ molly.cole@po.state.ct.us

KAREN ZRENDA

5 Dogwood Drive
Old Lyme, CT 06371
Fax: (203) 764-8190

❖ (203) 764-8180

❖ Karen.Zrenda@yale.edu



ADVOCACY IN ACTION:

In 2006, FV of CT:

- ☑ Distributed nearly 1,000 newsletters
- ☑ Distributed almost 1,400 additional hardcopy materials to families
- ☑ Informed 969 families and professionals by participating in 45 meetings



Family Voices of Connecticut (FV CT) engages families in a number of ways to promote quality of health care services for CYSHCN. These include assistance provided through individual support, training, parent matching, support groups, listservs, conferences, and materials such as a Care Notebook. Funding to support these activities is provided by the State of Connecticut Department of Children and Families, DHHS Center on Medicare and Medicaid, CMS Family-to-Family grant, CT Health Foundation, Tow Foundation, and the New Haven Foundation.

2006 HIGHLIGHT: *Shaping Legislation*

Family Voices was an active participant in a legislative summit focused on legislation to implement the Family Opportunity Act (FOA) and to expand the Katie Beckett Waiver in CT. A panel presentation featuring Julie Beckett, FV's Director of National Policy, and the Catalyst Center provided information on the history of FOA, its potential impact, and its potential costs in Connecticut. The legislation continues to have support.



Katie Beckett and Julie Beckett, Director of National Policy, Family Voices

BUILDING PARTNERSHIPS: *Families and Policy-Makers*

FV CT is instrumental in bringing the voice of families to the table by:

- ☑ Supporting families financially and in other ways to participate on the Medical Home Advisory Council
- ☑ Co-sponsoring two summits on CYSHCN with parent and state agencies, resulting in state legislation to provide an oversight council for CYSHCN.
- ☑ Mobilizing families and providers, in partnership with the CT Office of the Child Advocate, to focus state legislative attention on CYSHCN

"The parent input in the meetings has been incredibly powerful and constructive to the dialogue."

- a parent, speaking about the Medical Home Advisory Council

Family Voices of Delaware



BETH A. MACDONALD

35 West Fairfield Dr
Dover, DE 19901
Fax: (302) 698-1778

- ❖ (888) 835-5669
- ❖ bethappenzeller@aol.com

ANN PHILLIPS

3301 Englewood Rd
Wilmington, DE 19810
Fax: (302) 478-3350

- ❖ (302) 831-2028
- ❖ aPhillip@udel.edu

BRUCE ORR

502 WS. 36th St
Wilmington, DE 19802
Fax: (302) 762-7809

- ❖ (302) 761-9347
- ❖ Bruce4093@aol.com



ADVOCACY IN ACTION:

In 2006, FV DE:

- Distributed information through 400 special needs newsletters and e-newsletters
- Informed 880 families and professionals by participating in 32 meetings
- Reached 163 families and professionals, on average, through listservs each quarter

Family Voices of Delaware (FV DE) assists families of CYSHCN and the professionals who serve them through: direct information and referral, parent matching, support groups, conferences, topical calls, resource guides, listservs, newsletters, and surveys. FV DE monitors legislative action that will impact families and works closely with other families and Delaware Medicaid to improve services for CYSHCN. FV DE is funded by the DE Maternal and Child Health Program, DE Emergency Medical Services for Children (EMSC), Easter Seals, the University of Delaware Center for Disabilities Studies, and the DE Early Intervention Program.

2006 HIGHLIGHT: *Partnering Families with EMS Personnel*

FV DE has been instrumental in the ongoing success of the Special Needs Alert



Program (SNAP), a collaborative effort with EMSC to connect families of CYSHCN with their local emergency medical services. Through this innovative program, a model for other states, CYSHCN are identified

and critical medical information from parents and providers is shared with local paramedics. In the event of an emergency, emergency personnel have easy access to the medical information they need before they arrive. Currently there are 70 families registered in SNAP. In 2006, SNAP families, paramedics and ambulance BLS staff were surveyed in order to evaluate the program. Results indicate that SNAP has been very effective in educating families and emergency personnel and helping them work as a team.

"To have established this level of cooperation and collaboration among families, pediatricians, EMS personnel, and emergency room personnel is to be commended."
- Special Needs Alert Program Survey Report

WORKING TOGETHER FOR CYSHCN:

FV DE partners with many organizations to improve care for CYSHCN:

- University of Delaware Center for Disabilities Study
- Governor's Advisory Council for Exceptional Citizens
- Birth to Three Program
- Autism Society of Delaware
- Partners in Policy Making
- Easter Seals
- Little People of America
- DE MetDESK specialist
- United Cerebral Palsy
- Down's Syndrome Association
- Delaware Developmental Disabilities Council

Family Voices of DC



DOREEN HODGES

4363 Barnaby Rd SE Apt 204
Washington, DC 20032

❖ (202) 230-8201

❖ kingtitusmom@yahoo.com

GAIL JOHNSON ANDERSON

5558 B-Street SE
Washington, DC 20019
Fax: (202) 448-1451

❖ (202) 448-1462

❖ gailjanderson@yahoo.com



ADVOCACY IN ACTION:

Family Support

The following is an example of effective support that FV of DC provides on an ongoing basis to the families of DC. A Mom, with special needs, needed therapy services and basic health care for her two children with special needs, but the family had no health insurance. They were referred through an HMO to FV of DC. FV of DC was able to help the family complete the paperwork and contact the appropriate office and in under 30 days, the Mom and the two children were back on Medicaid.



Family Voices of DC (FV of DC) provides information and support to families of CYSHCN and the professionals who serve them in several ways: direct support, parent matching, training, focus groups, topical calls, listservs and conferences.

2006 HIGHLIGHT: *Building Capacity*

FV of DC is taking steps to expand its capability to assist families and professionals. FV of DC is formalizing its infrastructure and has a new Executive Director, who will put into place a new Board of Directors and an Advisory Council of parents. It is expected that these steps will promote FV of DC as a key player in the District. FV of DC has been re-establishing its connections with key partners, including Title V.

BUILDING PARTNERSHIPS: *Developing Family Leadership*

FV of DC works with numerous families within DC who need help in establishing eligibility for their children on Medicaid including waivers and spend downs. FV of DC helps families:

- * complete forms needed to access Medicaid
- * select Medicaid HMOs from within their choices
- * connect with the Medical Assistance Program Administration

WORKING TOGETHER FOR CYSHCN:

During 2006, FV of DC worked in partnership with other advocacy groups including Autism Speaks and Health Insurance Partnerships within Families USA on improving rehabilitative services for CYSHCN. A bill was introduced in the District to stop insurance companies from limiting rehabilitative services for children with developmental disorders such as cerebral palsy. FV of DC provided testimony about the importance of these services for CYSHCN. Through testimony, and the hard work of these partners, the bill passed. The next step will be to provide trainings throughout the year to help families understand the bill and therefore get needed services for their children.



Family Voices of Florida

www.fifionline.org/FamilyVoices.htm



JESSICA DELGADO

520 Palm Dr.
Key West, FL 33040

❖ (877) 926-3514

❖ Jessicafhp@aol.com

BRANDY HEWETT

4650 Transport Rd
Bartow, FL 33830

❖ (877) 926-3514

❖ HewFLMOM@aol.com

JOHN REISS

Florida Institute for Family
Involvement
P.O. Box 35756
Gainesville, FL 32625-7567

❖ (877) 926-3514

❖ jreiss@fifionline.org



ADVOCACY IN ACTION:

In 2006, FV-FL@FIFI:

- ☑ Provided information and support in response to over 15,000 requests for assistance from families and professionals
- ☑ Distributed information in 2,200 newsletters
- ☑ Informed almost 15,000 families and professionals through participation in 130 meetings
- ☑ Reached over 1,700 families and professionals, on average each quarter by listserv

Family Voices of Florida at Florida Institute for Family Involvement (FV-FL@FIFI) provides information and support to families of CYSHCN and the professionals who serve them in many ways: individualized assistance, training, focus groups, conferences, parent matching, support groups, topical calls, resource guides, listservs, newsletters, website and surveys. FV-FL@FIFI provides and facilitates the voice of families in many state-level policy committees and legislative hearings. These activities are supported by funding from MCHB (F2F HIC grant), a Family Networking grant, and an Integrated Services grant.

2006 HIGHLIGHT: *Medical Home Project*

FV-FL@FIFI has implemented the Integrating Families, Communities, and Professionals (IFCAP) Medical Home project in three communities across the state. Each community (Jacksonville, SouthEast, and Sarasota) has an IFCAP Family Involvement Specialist, a parent leader who helps to ensure family involvement in all aspects of the project. Families who have a medical home are partners with medical professionals, and medical professionals are aware of resources within the community.

BUILDING PARTNERSHIPS: *Developing Family Leadership*

FV-FL@FIFI is instrumental in bringing the voice of families to the table:

- ☑ FV-FL@FIFI held the first ever Florida Policy Academy, focused on helping family leaders learn about the legislative process and where in the process that they can be most influential. The Academy was attended by ten adults and two youth leaders.
- ☑ FV-FL@FIFI continues to receive many calls on the toll free information and resource line to help families navigate systems of care. Through this resource families are given information to help them partner with state agencies and obtain needed services.



Family Voices of Georgia

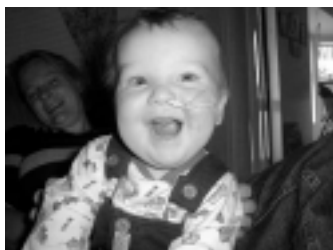


DEBRA S. TUCKER

Parent to Parent of Georgia, Inc.
3805 Presidential Parkway, Ste 207
Atlanta, GA 30340

❖ (770) 451-5484
(800) 229-2038

❖ debi@parenttoparentofga.org



ADVOCACY IN ACTION:

In 2006, FV of GA:

- ☑ Distributed information in almost 1,800 newsletters
- ☑ Informed 5,600 families and professionals through participation in 153 meetings
- ☑ Reached over 638 families and professionals, on average each quarter by listserv
- ☑ Distributed over 1,700 written materials



Family Voices of Georgia (FV of GA) advocates for families of CYSHCN through a number of activities: parent matching, training, focus groups, support groups, conferences, resource guides, listservs, website, newsletters, and surveys. This work is accomplished solely through volunteer effort. In 2006, Julia Bowen, former FV of GA Network Member, recorded 560 hours of volunteer time for Family Voices in helping the many families of CYSHCN in Georgia. FV GA has recently added a new Network member—Debi Tucker, from P2P GA who will work to share information with families of CYSHCN throughout the state.

2006 HIGHLIGHT: *Partnerships in Policy*

Recognizing her tireless efforts to help families and her positive impact on promoting programs, services and resources to improve the lives of people with disabilities, Julia Bowen was awarded “Advocate of the Year” in Georgia through a program funded by the Governor’s Council on Developmental Disabilities.

“I am very grateful to you for working so hard on this for (a child) ... God bless you. You're doing good work”
- a professional

WORKING TOGETHER FOR CYSHCN:

FV of GA has collaborated with other partners on many different activities:

- Working with all regional offices of the Division of Mental Health, Developmental Disabilities and Addictive Diseases (MHDDAD) to help place children in foster homes, medical models, or adoptive homes closer to their natural communities.
- Working as a Medicaid provider and licensed Child Placement Agency, Julia Bowen provided Medicaid waiver services to adults and children who are either medically fragile or have developmental disabilities.
- Working with state organizations to promote resources and services related to school placements and vocational rehabilitation services.

Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.
- Definition and Principles of Family-Centered Care (MCHB)

Family Voices of Hawai'i



LEOLINDA PARLIN

2604 Pauoa Rd.
Honolulu, HI 96813
Fax: (808) 531-3595

❖ (808) 282-6348

❖ leolinda@resqconsultants.com

JOSIE WOLL

378 Mamaki St
Fax: (808) 377-3779

❖ (808) 373-9713

❖ wolljosie@hawaii.rr.com



BUILDING PARTNERSHIPS: EPSDT

During this past legislative session, FV Hawai'i initiated legislation to convene a Statewide Screening Task Force to identify the barriers to the early and frequent screening of children within the medical home. They have worked very closely with HI Title V and AAP HI Chapter to develop guidelines and to further define the EPSDT well child visit to delineate the surveillance and screening requirements.



Family Voices of Hawai'i (FV Hawai'i) helps families and professionals work together to improve health care for CYSHCN in Hawai'i. This is done in a number of ways, including individual support, training, focus groups, surveys, conferences, and resource guides. Funding to support these activities is provided by HRSA (Integrated Service System Grant for CSHCN and the MCH LEND), CMS (Medicaid Infrastructure Grant), and ADD (Family Support 360 Project).

2006 HIGHLIGHT: *Expanding Training Opportunities*

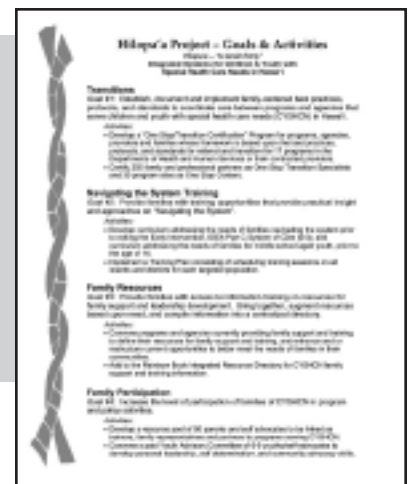
FV Hawai'i has worked in very close collaboration with the HI Medicaid agency to develop an outreach campaign and materials for consumers related to health plan enrollment, expanded eligibility, new benefits and new coverage groups. These outreach materials were based on feedback from focus groups of family members and other consumers supported by FV Hawai'i, a process which has now set the standard within the Department. *Real families with real stories* are highlighted in the materials.

BUILDING PARTNERSHIPS: *Families and Policy Makers*

FV Hawai'i has been very active in the DD/MR Waiver Policy Advisory Council, establishing guidelines for personal assistance services for children. FV Hawai'i has conducted the data analysis for the Council, which consists of families, providers and state personnel. This effort has provided insight into the family needs in developing the guidelines.

WORKING TOGETHER FOR CYSHCN:

FV Hawai'i is a partner in the Hilopa'a Project, along with the Hawai'i Department of Health-Children with Special Health Needs Branch, American Academy of Pediatrics-Hawai'i Chapter, and University of Hawai'i Department of Pediatrics-Community Pediatrics Institute. Hilopa'a ("to braid firmly" in Hawaiian) is an initiative to build integrated systems of care for CYSHCN in Hawai'i.



Family Voices of Illinois

www.thearcofil.org/
familytofamily/



FAYE MANASTER

The Arc of Illinois
18207-A Dixie Highway
Homewood, IL 60430
Fax: 708-206-1171

❖ (708) 560-6703

(866) 931-1110

❖ familytofamily@
thearcofil.org

ROSE SLAGHT

The Arc of Illinois
18207-A Dixie Highway
Homewood, IL 60430

❖ (815) 222-0659

❖ familytofamily2@
thearcofil.org



BUILDING YOUTH LEADERSHIP:

A comprehensive Family Manual for Transition, developed by FV IL/IL F2FHIC, the IL Dept. of Healthcare and Family Services, All Kids program staff and Health and Disability Advocates, was released in October 2006. This manual, available in CD, hard copy and on line, provides information about all aspects of IL's current system of services for youth with SHCN. It includes detailed information on health insurance options for youth in transition.



The Arc of Illinois Family-to-Family Health Information and Education Center/Family Voices of Illinois (FV IL) serves families and friends of children and youth up to age 21 who have special health care needs, disabilities and chronic illnesses. Services are provided in many ways including individual information and referral, focus groups, training and conferences, topical calls, family surveys, listservs, newsletters and resource guides. Funding for these efforts comes through a Family-to-Family Health Information and Education Center Grant from MCHB, a joint project of FV IL and the The Arc of Illinois.

2006 HIGHLIGHT: *Partnering to Develop Resources*

FV IL has developed and disseminated a number of publications for families, including:

- * Family Manual for Youth Transition,
- * Back To School Check-Up Guide,
- * Help with Your Questions Flyer (for families applying for SSI for their children),
- * IL Family-to-Family Health Information Center Brochure, and
- * Many other publications and resource lists available on their website:

<http://www.thearcofil.org/familytofamily/documents/documentmain.asp?DocSubTypeID=25>



These publications were developed through a collaborative review process that included the **Family Advisory Board of the Division of Specialized Care for Children**, and **Parent Partners from the Illinois Medical Home Project**, together with parent staff from the **Illinois Life Span Project** and the **Family Support Network**. Parents representing urban, rural, minority and immigrant families serve on FV IL's Project Advisory Board.

WORKING TOGETHER FOR CYSHCN:

FV of IL has successfully partnered with many other organizations to improve care for CYSHCN in IL, including:

- Engaging in joint activities with the IL State Title V CSHCN agency to share resources, provide and obtain technical assistance, review documents, and host meetings via teleconference to ensure parent participation.
- Collaborating with the IL Department of Healthcare and Family Services Medical Programs Division and the All Kids program to help individual families advocate for their children.

Family Voices of Indiana



MARY JO PALADINO

16130 Brockton Court
Granger, IN 46530
Fax: (574) 273-5208

❖ (574) 273-6019

❖ mpaladin@indiana.edu

DONNA GORE OLSEN

1130 E. 77th Street
Indianapolis, IN 46240
Fax: (317) 257-7446

❖ (317) 257-8681

❖ donnagoreolsen@aol.com



WORKING TOGETHER FOR CYSHCN:

FV Indiana has joined several state groups and organizations to form a coalition of groups to more effectively address issues affecting children and youth with special health care needs. FV Indiana has worked with other advocacy groups to address issues related to Medicaid Waivers. Partnering with EI programs, Head Start, the schools, Parent-to-Parent networks, PTI, and children's hospitals and transition programs has resulted in: increased family involvement in policy development; increased family representation in committees and workgroups; increased information sharing among entities that impact families; and increased information sharing to families.



Family Voices of Indiana (FV Indiana) provides assistance to families of CYSHCN in a many ways: direct support, conferences, focus groups, support groups, parent matching, training and topical calls, printed materials, listservs and a library/lending program. Funding from the Family Social Services Administration, the Department of Education, Division of Exceptional Learners, and Maternal and Children's Special Health Care Services (Title V, Indiana State Department of Health) has supported these efforts. Staff of FV Indiana have volunteered over 260 hours in providing assistance to families and professionals.

2006 HIGHLIGHT: *Families and Policy Makers*

FV Indiana facilitated and supported parent involvement in policy decisions by sending action alerts via the FV Indiana listserv. In 2006, parents provided public comment to the State Advisory Council on Special Education and provided input on Medicaid Waivers during public hearings. Members of FV Indiana's leadership represented the parent perspective in a variety of initiatives including: Sunny Start (formerly the Early Childhood Comprehensive Systems Grant), revisions of the Medicaid Waiver Consumer Manual, Medicaid Waiver Wait-List Committee, Part C Family Perspectives, IN-SIG (Indiana State Improvement Grant), State Mental Health Linkage Project and the Indiana Center for Youth and Adults with Conditions of Childhood at the Indiana University School of Medicine.

BUILDING PARTNERSHIPS: *Developing Leadership*

FV Indiana is excited to report that the FV Indiana listserv (groups.yahoo.com/group/FVIndiana), dedicated to sharing information related to family input into policy, procedures and program decisions that impact families with children who have disabilities, developmental delays and/or significant medical needs, was launched in August of 2006. Currently, the listserv has over 150 direct subscribers and reaches hundreds of additional families via information sharing within existing family networks.



Family Voices of Iowa

www.askresource.org



PAULA CONNOLLY

Health Information Center
321 East Sixth Street
Des Moines, Iowa 50309
Fax: (515) 243-1902

❖ (800) 450-8667
(515) 243-1713

❖ f2finfo@askresource.org



DEVELOPING FAMILY LEADERSHIP:

FV of IA, in collaboration with the Dept of Education, provides a statewide leadership training called "Parents as Presenters." Families of CYSHCN learn skills on how to effectively share their unique stories with policymakers and professionals. When they complete the training, participants join a statewide Speakers Bureau.



Family Voices of Iowa (FV of IA) is one of many programs within Access for Special Kids (ASK) Family Resource Center. Services include a broad range of information, advocacy, support, training and navigation help for families of special kids and youth in Iowa through:

- * individualized support
- * support groups for diverse populations
- * advocacy activities using listservs, focus groups, surveys, and newsletters
- * family mentoring
- * training workshops thorough multimedia access

ASK is a non-profit 501(c)(3) receiving funding supports from a variety of state, and local grants as well as private donations.

2006 HIGHLIGHT: Health Care Financing

During the recent legislative session, FV of IA advocated for the passage of an Iowa Medicaid buy in program under the FOA for children and youth with special health care needs. This will provide families expanded flexibility and give families more options to meet the health care needs of their children. In January, 2007, IA received a "money follows the person" CMS grant. FV of IA is actively involved in stakeholder workgroups and subsequent sub-committee groups that are defining how this grant is implemented within the state.

WORKING TOGETHER FOR CYSHCN

FV of IA is in the initial planning stages of identifying roles of family advocates and various partner organizations to help achieve the MCHB six core performance measures to achieve access for all children/youth with special health care needs within community based systems of care. A template helps identify:

- what each group is doing,
- service gaps or needed system changes
- response roles groups can assume, weaving a statewide network together into an effective "change template."

Families are the core of this nation's health system, their children's most important health providers and caregivers.

-a Family Voices Principle

Family Voices of Kansas



SUSAN ARNOLD

501 SW Jackson, Suite 400
Topeka, KS 66603
Fax: (785) 233-4787

❖ (785) 233-4777

❖ ptp@
families-together-inc.org



ADVOCACY IN ACTION:

In 2006, FV KS and Families Together:

- Distributed over 33,000 newsletters
- Reached over 13,000 families and professionals through participation in 979 meetings
- Provided assistance for families and professionals on almost 3,100 occasions
- Topics of information provided included:
 - ❖ Disabilities
 - ❖ Education
 - ❖ Early Intervention
 - ❖ Advocacy
 - ❖ Partnering
 - ❖ Parent-to-Parent support
 - ❖ Transition
 - ❖ Oral Health
 - ❖ Community Resources
 - ❖ Medical Home



Family Voices of Kansas (FV KS) is a project of Families Together, a statewide non-profit organization assisting Kansas families which include sons and/or daughters who have any form of disability. FV KS and Families Together collaborate to help families of CYSHCN and the professionals who serve them by providing: individualized information and support, training, focus and support groups, parent matching, listservs, newsletters, and conferences. Funding to support these activities is provided by the US and KS Departments of Education and the KS Department of Health and Environment, and KS Department of Social and Rehabilitation Services.

2006 HIGHLIGHT: *Partnering with Title V*

FV KS participates in a Family Advisory Group to help shape the programs and policies of Title V – Special Health Services in Kansas. This group meets by conference call on a quarterly basis and in-person once a year.

WORKING TOGETHER FOR CYSHCN:

FV KS and Families Together partner with many other organizations to improve the lives of families of children with disabilities. Highlights from 2006 include:

- Working with parents, advocates, and a coalition of organizations to advocate for guidelines and regulations on seclusion/restraint of children in schools
- Collaborating on an RFP for a Comprehensive Employment Grant Planning project.



Family Voices of Kentucky



DEBBIE GILBERT

982 Eastern Parkway
Louisville, KY 40217

❖ (502) 595-4459 x.279

❖ Debbie.Gilbert@ky.gov



ADVOCACY IN ACTION:

In 2006, FV of KY:

- ☑ Provided individual assistance to over 300 family members and professionals
- ☑ Informed and educated over 340 families and professionals by participating in 26 meetings
- ☑ Reached an average of 425 people through listservs each quarter



Family Voices of Kentucky (FV of KY) is supported by and housed within the state's Title V Program. FV of KY offers the family perspective in Title V policy discussions and through participation in state-level committees, and provides information and support to families through individual interaction and listserv discussion. FV of KY is working with families to improve health care services and building partnerships between agencies and families in Kentucky. Future trainings for families are planned on such topics as parent-to-parent support, transition, and educational needs.

FV of KY is working with Medicaid in the redesign of some of the state waiver programs. They assist families in learning how to navigate systems and advocate for their children.

2006 HIGHLIGHT: *Parent Advisory Council*

A key project in 2006 has been the establishment of a Parent Advisory Council(PAC) for the Title V Program. To further its mission, the Council has completed a strategic plan focusing on advocacy, education and communication.

The Parent Advisory Council plans to be involved in several exciting projects. These include the development of a brochure to inform other parents about the PAC and the availability of their support and participation in staff interviews for the Commission for Children with Special Health Care Needs (CCSHCN). The PAC is working to educate legislators concerning the needs of CYSHCN and the impact legislation will have on these families. The PAC is excited about forming a Parent-to-Parent program.



WORKING TOGETHER FOR CYSHCN:

FV of KY collaborates with many organizations, including:

- United Partners in Kentucky
- Protection and Advocacy
- The Arc of Kentucky
- Kentucky SPIN (PTI)
- Family-to-Family

Family Voices of Louisiana



PHYLLIS LANDRY-RATCLIFF

429 Enon Sartinville Rd
Jayess, MS 39641
Fax: (504) 586-9170

❖ (504) 299-9175
(504) 299-9176
(866) 470-7990 (LA)

❖ familyla@bellsouth.net

LAMAR LANDRY

❖ lamar70056@yahoo.com

ALBERT TRUEHILL

❖ ecsr@dhhs.la.gov



WORKING TOGETHER FOR CYSHCN:

FV of LA has provided the family perspective to 39 organizations and work groups through family representation at over 70 meetings, participation in six statewide town hall meetings, and in numerous discussions. FV of LA partners with:

- ❖ Mental Health coalition
- ❖ Office of Public Health
- ❖ Children's Special Health Services
- ❖ Community Disaster Preparedness Agency
- ❖ Medical Home Coalition
- ❖ Injury Prevention Program



Family Voices of Louisiana (FV of LA) offers support and information to families of CYSHCN in many ways:

- * individualized support
- * support groups
- * parent matching
- * training
- * focus groups
- * conferences
- * lending library
- * resource guides
- * care notebook
- * surveys
- * listservs
- * newsletters
- * videos

Funding from CMS as a Family-to-Family Health Information and Education Center supports this effort.

2006 HIGHLIGHT: *Partnering with Title V*

Family Voices of Louisiana is providing assistance to the many families of CYSHCN needing help navigating the systems of care in Louisiana, a population representing almost 16% of all children and 23.2% of all households* in the state. In Louisiana, close to 40% of currently insured CYSHCN have coverage that is not adequate and almost 16 % of CYSHCN were without insurance at some point during the past year. These statistics underscore the reasons families need help in navigating systems of care in Louisiana. With funding from the F2F HIC grant, Family Voices of Louisiana provides needed information to families about health care, mental health, and disaster preparedness.

BUILDING PARTNERSHIPS: *Families and Community-Based Services*

FV of LA works with many families and organizations on the Neighbor Liaison Project. FV of LA was asked to head this project because the state needed an organization with a history of working with families and organizations at every level in the community. FV of LA has a history of partnering with many organizations throughout the state of Louisiana since 1992. Through the Liaison project, FV of LA provides data on a monthly basis about the number of families, schools, and businesses that have relocated back to specific areas of New Orleans. This data is used by the city to help track the movement of citizens relocating back to these hurricane damaged areas.

"Family Voices of LA continues to build strong, long-lasting relationships and bridges for families and professionals in the state of Louisiana."

- a professional

* Child and Adolescent Health Measurement Initiative (2005). National Survey of Children with Special Health Care Needs Data Resource Center. Retrieved 04/02/07 from www.cshcndata.org

**Family Voices of
Maine**

www.mpf.org/SPIN/
FamilyVoices/MaineFV.html



BEVERLY BAKER

Box 2067
Augusta, ME 04338-2067
Fax: (207) 623-2148

❖ **(800) 870-7746 (ME)**
(207) 623-2144

❖ **bbaker@mpf.org**



**BUILDING PARTNERSHIPS:
Developing Family
Leadership**

Family Voices of Maine offers workshops on Building Partnerships to assist families and youth to be more comfortable with advocating within systems, working with legislators and serving on policy setting committees.

“Sherry is a parent who has become a strong advocate for her child. She recently sent a letter to the Governor expressing her concerns about availability of services in a rural area of Maine...With help from our advisory/support group she has gained knowledge and confidence and now serves on the State’s System of Care Board.”

- Family Voices of Maine
regional staff



Family Voices of Maine offers support and information to families of CYSHCN through several venues, including conferences, focus groups, support groups, listservs, newsletters, direct support, parent matching, training, resource guides, care notebooks, surveys, lending library and website. Funding from several sources supports this effort, including MCHB (Integrated Services Grant and F2F HIC Grant), SAMHSA, ME DOE, ME Dept of HHS, CSHCN/Title V (Newborn Hearing Grant).

2006 HIGHLIGHT: Parent Advisory Council

With a second round of funding from MCHB as a Family-to-Family Health Information Center (F2F HIC), Family Voices of Maine focuses on expanding assistance to families of CYSHCN, a population representing 16% of all children and 24% of all households* in the state. In Maine, 40% of families of CSHCN are under 200% of the Federal Poverty Level (compared to 26% nationwide)*, underscoring the importance of public health care to many families. With funding from the F2F HIC grant, Family Voices of Maine looks forward to:

- * continuing their regional family support work across Maine,
- * expanding their Parent-to-Parent program,
- * increasing their parent leadership through advocacy and legislative workshops, and
- * exploring exciting new partnerships with organizations with similar missions.

WORKING TOGETHER FOR CYSHCN:

Family Voices of Maine has collaborated with many partners in 2006 to improve care for CYSHCN, including working with DHHS to help reinstate specific benefits, positively affect eligibility standards, and reduce proposed premium payment under Medicaid - Katie Beckett waiver program. Other partners have included :

- CSHN program System of Care grantees
- NICU at Maine Medical Center
- Jason Program
- Healthy Maine Communities
- American Lung Association of Maine
- Regional Children’s Cabinets
- Maine Doe’s Committee on Transition
- Title V’s Newborn Hearing Program
- Pediatric Hospice Program
- Maine Equal Justice Partners (a legislative & legal advocacy organization giving low-income people an effective voice on issues they care about)
- Hi-Fidelity WrapAround Projects (serving families of children with severe emotional disorders)

“Through the mentorship programs and youth leadership, I (have) met new friends, helped other youth to join, and learned what I wanted to do with my life. With the encouragement and help of the group, I decided that I wanted to finish my high school years early in preparation for the career I have chosen.”
- A youth mentor and leader

* Child and Adolescent Health Measurement Initiative (2005). National Survey of Children with Special Health Care Needs Data Resource Center. Retrieved 04/02/07 from www.cshcndata.org

Family Voices of Maryland



GRACE PUSHPARANY WILLIAMS

801 Cromwell Park Drive
Suite 103
Glen Burnie, MD 21061
Fax: (410) 768-0830

❖ (410) 768-9100
(800) 394-5694

❖ grace@ppmd.org



BUILDING PARTNERSHIPS: *Families and Providers*

MDFV shares the family perspective with many Federal, State and local agencies by participating on a variety of task forces and advisory committees. MDFV enjoys ongoing partnerships with:

- ❖ Maryland Title V
- ❖ Medicaid
- ❖ MCHB
- ❖ Department of Health and Mental Hygiene
- ❖ Department of Education,
- ❖ AAP-MD Chapter
- ❖ DD Council
- ❖ Coalition of Children's Mental Health
- ❖ Special Needs Children's Advisory Committee
- ❖ Medicaid Advisory Committee
- ❖ UCEDD Advisory Committee
- ❖ State Interagency Coordinating Council (SICC)
- ❖ hospitals and academic centers.

Working together with these partners, MDFV has been able to ensure that the voices of families are included in the process and development of policy at all levels of care.

The activities of **Family Voices of Maryland (MDFV) at The Parents' Place of Maryland (PPMD)** focus on helping families partner in decision making for their children and on improving the system of care. MDFV provides assistance to families in many ways, including individual information and referral, parent matching, advocacy, training, and leadership skills development. Information and resources on many topics are shared through one-on-one contact, trainings and conferences, videos, listservs, e-mail newsletter, and PPMD website. A health care survey of parents on access to care and Medical Home showed that families, for the most part, prefer getting information from parent organizations and that financial hardship is fairly common across all families of CYSHCN, including loss of employment income and extraordinary expenses. These efforts are supported by funding from Maryland's Title V agency and a CMS Family-to-Family Health Information Center grant.

2006 HIGHLIGHT: *Leadership Development*

MDFV implemented an eight-month long training program for parents of CYSHCN. Topics included the parent movement in health care, family-centered care, cultural competency, MCHB's 2010 objectives, how to effectively access private and public health insurance, and legislative activities related to health care in the state. Meetings with state legislators were the highlight of one of the training sessions. As result of this program, participants have increased their involvement in health care policy across the state, participating in a variety of task forces and advisory communities at the local and state levels.



WORKING TOGETHER FOR CYSHCN:

MDFV @ PPMD is very involved with partners in 2010 Activities:

- ☑ **Medical Home:** Collaborating with Title V and AAP to implement the Medical Home State Plan, including "10 Around the Table" to educate pediatric practices.
- ☑ **Insurance Coverage:** Collaborating with Medicaid to ensure parent involvement by placing a MDFV staff member at Medicaid state office to work on policy issues.
- ☑ **Screening:** Providing mini-grants and support to parent support groups for deaf and hard of hearing families statewide as part of newborn hearing screening activities with MD's Title V.
- ☑ **Family Participation:** Providing leadership development to diverse parents in inner cities and rural communities to strengthen their capacity to impact public policy.
- ☑ **Transition:** Development of a web-based tutorial for parents and youth with special health care needs in collaboration with Title V.

Family Voices of Massachusetts

www.massfamilyvoices.org



BETH DWORETZKY

Mass Family Voices @ Federation for
Children with Special Needs
1135 Tremont St, Suite 420
Boston, MA 02120
Fax: (617) 572-2094

❖ (800) 331-0688 x.210 (MA)
(617) 236-7210 x.210

❖ massfv@fcsn.org



WORKING TOGETHER FOR CYSHCN:

In 2006, Mass Family Voices developed a key partnership with the **MA Department of Public Health, Office of Oral Health**, to ensure family participation in the development of a MA Oral Health Action Plan for CYSHCN. In this activity, Mass Family Voices helped tailor the statewide oral health forums to accommodate families' schedules; worked with the Department to arrange stipends for families to attend; and posted the forum questions to the project website and listserv so families would have alternative ways to participate in lieu of attending the forums. Finally, Mass Family Voices used its extensive networks to distribute the plan for families' feedback, which the Office of Oral Health incorporated into the final version.



Mass Family Voices (Mass FV), a project of the Federation for Children with Special Needs (FCSN), is currently funded through a 2004 CMS grant as a Family-to-Family Health Care Information and Education Center. Staff provides information about the MA public benefits system and medical advocacy support to families with children and youth with special health care needs (CYSHCN). Mass FV offers support to families and professionals through a variety of venues: direct contact, a listserv, a website, a lending library, newsletter articles, topical conference calls, trainings, and through an annual parent leader conference.

2006 HIGHLIGHT: *Joining Voices Parent Leader Conference*

This annual conference is an opportunity for parents of CYSHCN to learn advocacy and leadership skills and to network with other families throughout the Commonwealth. The highlight of Joining Voices 2006 was keynote speaker, Patti Hackett, Co-Director of the Health and Ready to Work National Resource Center. Patti's presentation, "Preparing for Life: Survive & Thrive!" was a humorous, poignant and inspirational discussion about strategies families can use to move forward when the dreams they had for their child had to change. Participants attended a variety of afternoon workshops to learn strategies to advocate for quality health care services not only for their child, but also for all children with special health needs. Although family leaders actively discuss issues, and support one another through the Mass FV listserv, there is nothing quite like the excitement and synergy generated when parents of CYSHCN get together in person.



Patti Hackett (middle) with participants at Joining Voices

"We have a five year old child on the autism spectrum. To enable our son to fully participate in the community requires maximizing available resources. Understanding, however, the MA public benefits and community resources available to him seemed an insurmountable task. I never could have come to know or navigate these complex systems without the help I received from Mass Family Voices.

On numerous occasions, Mass FV informed me of applicable public benefits and community resources and assisted me in obtaining and accessing them. The project helped me re-obtain benefits when 'glitches in the system' dropped our son.

In addition to being a parent of a disabled child, I work in the family court and participate in my school district's special education parent advisory council. In all three capacities, I have been able to share much of the information Mass FV has provided and direct people to the project for further assistance. I personally and professionally know that Mass FV has assisted many families in MA."

- a parent

Family Voices of Michigan

www.bridges4kids.org/f2f/



BEV CRIDER

Children's Hospital of Michigan
3901 Beaubien
Detroit, MI 48201

❖ (313) 745-0197

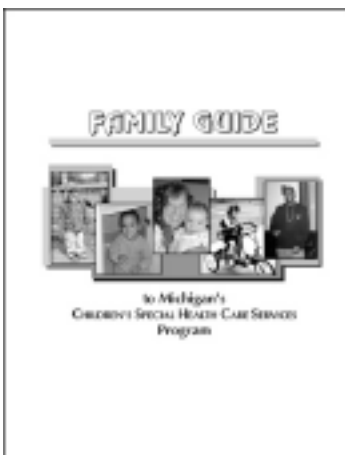
❖ bcrider@dmc.org

MARY MARIN

Michigan Department of Community Health
CSHCN Services Division
Lewis Cass Bldg, 6th Floor
320 Walnut St
Lansing, MI 48913
Fax: (517) 335-8055

❖ (517) 241-7197

❖ marinm@michigan.gov



The Michigan Family-to-Family Health Information and Education Center (F2FHEIC), as a FV partner (Family Voices of Michigan), provides a wide range of services to families to help them navigate the health care systems for CYSHCN in Michigan. These include: individual information and referral, focus groups, training, parent matching, conferences, topical calls, surveys, lending library, listserv, newsletters, and website. Funding to support these activities is provided by CMS.

2006 HIGHLIGHT: Building Family Leadership

F2FHEIC has developed sophisticated, substantial training modules to develop family leadership and professional partnerships. Some of these series include:

- * CSHCS (Children's Special Health Care Services) 101 for Medicaid Health plans and others, including private insurers such as Blue Cross Blue Shield of Michigan
- * How to Access Mental Health Services For Your Child Using Public or Private Healthcare Coverage
- * Will Your Teen be Ready For Adult Life?
- * Health & Education (public health care coverage, special education, etc.)
- * Health Resource Support Parent
- * Project Resilience Train the Trainers



Trainings may be offered both on-site and on-line. Information about additional trainings from other organizations is also available on the F2FHEIC website.

WORKING TOGETHER FOR CYSHCN:

F2FHEIC partners with many other organizations to improve care for CYSHCN, including:

- Title V Agency – As a parent partner employed by Title V, Family Voices of MI participates on an ongoing basis with representatives from SCHIP and Medicaid programs.
- Region IV Genetics Committee
- AMCHP Family Advisory Committee
- AMCHP Board
- MI Developmental Disability Council Health Issues Workgroup

Family Voices of Minnesota

www.familyvoicesofminnesota.org



CAROLYN ALLSHOUSE

Building Communities for CYSHCN
Minnesota Children with Special Health
Needs
Department of Health
PO Box 64882
St. Paul, MN 55164-0882
Fax: (651) 201-3655

❖ (651) 201-3653

❖ [www.network@
familyvoicesofminnesota.org](http://www.network@familyvoicesofminnesota.org)

JOHN HOFFMAN

❖ (763) 315-1094

❖ [jhoffman@
midwaytraining.com](mailto:jhoffman@midwaytraining.com)

AMY DAWSON

PACER Center
8161 Normandale Blvd
Minneapolis, MN 55417-1098

❖ (952) 838-9000
(800) 527-2237

❖ amy.dawson@pacer.org



Family Voices of Minnesota (FV MN) connects families with one another through trainings, conferences, and focus groups covering a variety of topics including, but not limited to Medicaid, Medicaid Waivers, Private Insurance/HMOs, Youth Leadership, and Transition to Adult Care. Likewise, FV MN provides information and assistance to families of CYSHCN through an e-mail network, website, printed materials including newsletters and care notebooks, and mailings. FV MN connects families with local, state and national committees to promote parent/professional collaboration across all systems. These activities are done through partnership among the Minnesota Children with Special Health Needs Program, PACER Center and volunteer families.

2006 HIGHLIGHT: *Developing Family Leadership*

Through a partnership between the Minnesota Children with Special Health Needs program (Title V) at the Department of Health, PACER Center's Family-to-Family Health Information Center and Early Childhood project, a state wide Family Leadership Summit was held in April 2006. The summit brought together parents of CSHCN and/or disabilities to enhance their leadership skills and to connect family leaders with one another on a local, regional and state level. The second annual Family Leadership Summit will be held in April 2007.

BUILDING PARTNERSHIPS: *Families and Professionals*

FV MN has been very involved with other partners in activities that promote and support family/professional partnerships. The MN Chapter of the Academy of Pediatrics and the Minnesota Children with Special Health Needs program at the Department of Health have sponsored the development of a Children's Health Care Quality Consortium which includes parents from the Family Voices of Minnesota Network. Minnesota's Medical Home Collaborative currently has 21 teams across the state; every team includes two parents who have children with special health needs and/or disabilities.

WORKING TOGETHER FOR CYSHCN:

FV MN is working to create connections with all advocacy organizations in MN through the development of a Family Voices of MN Network Consortium. The Consortium will include parent representatives from disability advocacy organizations from across the state, family advisory committees, parents involved in systems level advisory committees and parents at large. The goal of bringing together these representatives is to have a forum that will coordinate and support family involvement and leadership activities throughout Minnesota.

Family Voices of Mississippi



POLLY JO DUNCAN

P.O. Box 786
Ripley, MS 38663

❖ (662) 587-5006

❖ pollyjod@hotmail.com

WILLIAM LE'RON JACKSON

5070 Kaybrook Drive
Byram, MS 39272

❖ (601) 373-1628

❖ wltj24@yahoo.com



ADVOCACY IN ACTION:

In 2006, FV of MS:

- ☑ Provided assistance to over 250 family members and professionals
- ☑ Informed and educated more than 1,242 families and professionals by participating in 48 meetings
- ☑ Reached an average of 437 people through listservs each quarter



Family Voices of Mississippi (FV of MS) is in a state of transition as they search for funding and organizational support to help them serve the many families of need in Mississippi. FV of MS Family Leaders volunteer their time and use personal resources to take calls from parents and other individuals with disabilities needing help. They provide information about:

- | | |
|-----------------------|-------------------------|
| * community resources | * respite |
| * advocacy | * health care financing |
| * transition | * education |
| * conferences | * support groups |
| * disabilities | * partnerships |



FV of MS helps families become aware of their rights and refers them to resources and programs available to them on a local, statewide and national level. FV of MS also monitors legislative action that has the potential to effect health care policy and informs families and colleagues of this impact.

2006 HIGHLIGHT: *Partnerships for Emergency Planning*

FV of MS is working with the Tippah County Emergency Management Association (TEMA) and the Special Needs Arc of MS to plan for the needs of persons with disabilities in the case of disasters and other emergencies. This partnership is creating a database of persons in the county who are disabled and/or elderly. By recording where they live (complete with directions), what their special needs are (special equipment, etc.) and other relevant information, resources can be assembled as quickly as possible in the case of an emergency. In the event of a tornado or earthquake, for example, these resources might include volunteers able to bring chainsaws to cut trees, people with vans to pick up the person with a disability or people willing to deliver food and supplies to those in need.

WORKING TOGETHER FOR CYSHCN:

FV of MS works with many organizations, providing a family perspective and staying on top of changes in the complicated health care systems and services for CYSHCN. This involvement includes working with:

- Medicaid
- Medicare Social Security
- Met Life
- Timber Hills Mental Health
- N. MS Regional Facility

Family Voices of Missouri

www.familyvoicesofminnesota.org



CARLA SANDWELL

811 N. Fremont Avenue
Springfield, MO 65802

❖ (417) 619-2609

❖ fvmo@mchsi.com

DEANA O'BRIEN

1121 Curtis Street
Mexico, MO 65265
Fax: (573) 581-1026

❖ (573) 581-7887 x30

❖ dobrien@arthurcenter.com



BUILDING PARTNERSHIPS: *Families and Policymakers*

Through a partnership between stakeholders, a massive effort is underway to pass Missouri's Senate Bill 621 (SB 621). SB621 changes the name of the "Division of Mental Retardation and Developmental Disabilities" to the "Division of Developmental Disabilities." Removing the term "mental retardation" advances the support of People First language in Missouri, a national trend and major focus for FVMO.



Family Voices of Missouri, Inc. (FVMO) shares information and resources with families of CYSHCN and the professionals who serve them in a variety of ways such as: listservs and web based information; newsletters and brochures; state, academic, public and private agency development; and family and professional leadership training on federal and state policy, family advocacy and partnering, child and family development, cultural diversity and competency, working with families and CYSHCN, child abuse and neglect prevention, and physical, mental and oral health.

2006 HIGHLIGHT: *Focus on Mental Health Capacity Building Partnerships*

- * The National Assembly on School-Based Health Care (NASBHC), through a collaborative agreement with the University of Missouri-Columbia, is partnering with FVMO & other stakeholders to embark on a new initiative to build capacity of state and local education agencies (SEA's & LEA's) to provide effective and sustainable school mental health services to young people. The goal of this initiative is to disseminate model mental health policies, programs & services to SEA's/LEA's in order to improve access to high quality, school-based mental health services. Missouri is one of only four states selected for this ground-breaking project.
- * With support from the Arthur Center, a community mental health partner, a weekly digest is electronically circulated statewide for parents and professionals alike. It is filled with information ranging from current legislation to parenting tips to spotlighting a mental health topic and much more.

WORKING TOGETHER FOR CYSHCN:

A sample of some of the activities in which FVMO partnered with others in 2006:

- Participated in Missouri's CYSHCN Family Advisory Council, Family Partnership
- Assisted with creation and introduction of federal legislation titled Shaken Baby Syndrome Prevention Act of 2007
- Informed families and legislators of disability awareness legislation, meeting with legislators in Missouri and Washington, D.C.
- Worked with Friends of the Thompson Center for Autism and Neurodevelopmental Disorders
- Served on the Missouri Assistive Technology Council (MoAT)
- Educated elementary education and child development college majors on "how to" work with families and CYSHCN

"Partnering with family members is essential to creating sound public policy that supports systems that are effective and efficient. It is a partnership that we cannot afford to do without."
- CSHCN Director

Family Voices of Montana



DENNIS MOORE

516 North 32nd St
Billings, MT 59101
Fax: (406) 255-0523

❖ (406) 255-0540
(800) 222-7585 (MT)

❖ rholt@pluk.org

REBECCA ADAMS

P.O. Box 11510
Bozeman, MT 59719

❖ (877) 847-8890

❖ radams@pluk.org



WORKING TOGETHER FOR CYSHCN:

FV of MT works to bring the voice of the family to policy discussions on committees and groups such as:

- ❖ Special Education Advisory
- ❖ SOC/KMA (see box)
- ❖ MT Council on Developmental Disabilities
- ❖ Comprehensive System of Professional Development (CSPD)
- ❖ IDEA-PTA
- ❖ Montana Advocacy Program
- ❖ MT School for the Deaf & the Blind
- ❖ Regional Utah Leadership Education in Neuro-developmental Disabilities Program(URLEND)
- ❖ Newborn Hearing Screening
- ❖ Governor's Council on Disability
- ❖ Developmental Disability Program
- ❖ ABCD Screening Academy
- ❖ Parent Center Alliance



Family Voices of Montana (FV of MT) is a project of Parents, Let's Unite for Kids (PLUK), a parent-run organization that provides families of children with disabilities and chronic illnesses the information, support, training and assistance to aid their children at home, school and as adults. With funding from CMS as a Family-to-Family Health Information Center, FV of MT provides assistance in a number of ways:

- | | | |
|--------------------------|--------------------------|-----------------|
| * individualized support | * conferences | * topical calls |
| * support groups | * online lending library | * listservs |
| * parent matching | * resource guides | * newsletters |
| * training | * care notebook | * website |
| * technology center | * videos | * surveys |

2006 HIGHLIGHT: *Partnerships for Emergency Planning*

FV of MT is developing a **Health Care Resources handbook and website** for families to help them navigate the health care systems in MT. The handbook will be available soon both as a downloadable version on the PLUK website and in hard-copy. The website will contain more comprehensive information and will be updated as information changes. This project is funded through the Otto Bremmer foundation and the state Children's Special Health Services.



BUILDING PARTNERSHIPS: *Focus on Youth and Transition*

FV of MT and PLUK partner with many agencies and community organizations to improve care for CSHCN:

- Within the Children's System of Care Planning Committee (SOC Committee), PLUK helps to coordinate the development of the State's system of care for high-risk youth and their families - Kids Management Authorities (KMAs). KMA's are parent-driven and give families and youth the opportunity to be active partners in decisions regarding their care. Partners on this committee include parents, providers, and advocates, including Native Americans.
- With the Rural Institute and MCDD, PLUK participates in the Partnership for Transition Project, an initiative for and by youth that:
 - focuses on youth strengths, needs and goals for the future
 - works with schools, community agencies and businesses
 - includes a statewide training component
 - is a model that will be expanded in the future

Family Voices of Nebraska

www.pti-nebraska.org



CHRIS REED

113 South 50th Avenue
Omaha, NE 68132

❖ (800) 284-8520 (NE)

❖ chrismreed@cox.net

GLENDA DAVIS

PTI Nebraska
3135 N 93rd St
Omaha, NE 68134
Fax: (402) 934-1479

❖ (402) 934-1488
(800) 284-8520 (NE)

❖ gdavis@pti-nebraska.org



ADVOCACY IN ACTION:

*In 2006, FV NE and PTI
Nebraska:*

- Provided assistance for families and professionals on almost 3,000 occasions
- Distributed almost 6,000 newsletters and 52,000 printed materials
- Informed, on average, 4,380 individuals each quarter through listservs
- Reached over 3,000 families and professionals through participation in 164 meetings



Family Voices of Nebraska (FV NE) is hosted by the Parent Training and Information Nebraska (PTI Nebraska), a statewide training, information and support organization for parents in Nebraska who have a child birth through twenty six with special needs. FV NE and PTI Nebraska collaborate and leverage their expertise in early intervention, special education and health services for children with special medical needs to help families and professionals. This is done in a number of ways, including: individual support, training, lending library, listservs, conferences, and surveys. Funding to support these activities is provided by the US and Nebraska Departments of Education and NE Developmental Disabilities Council.

2006 HIGHLIGHT: *Building Family Leadership*

PTI Nebraska held its first statewide conference for families. Co-sponsors were:

- * The Arc of Nebraska,
- * Learning Disabilities Association of Nebraska,
- * Protection and Advocacy,
- * Down Syndrome support group
- * Nebraska Federation for Families

"Because of your information, I was clear, concise and in control. I only had to swallow hard one time and did not lose control once. I am so grateful for all your help."

- a parent

The conference was funded by a grant from the Nebraska Developmental Disabilities Council. There were 75 in attendance including 59 parents, many of whom have CYSHCN. The evaluations were very positive, and it is hoped that the event can become an annual affair. Some families drove over 500 miles to attend.

WORKING TOGETHER FOR CYSHCN:

FV NE partners with many other organizations to improve care for CYSHCN. Highlights from 2006 include:

- FV NE facilitated the Title V Five Year Needs Assessment for CSHCN in 2005-2006 and continues to work with the task force that developed the three top priority needs for CSHCN in Nebraska. There is a "Transition" work group charged by the Office of Family Health to develop strategies for this top priority need and FV NE is an active participant.
- FV NE participated in a NE Early Childhood Comprehensive Systems Grant Program meeting to generate ideas about the formation of a task force to enhance health examinations provided through the EPSDT program and to promote Bright Futures guidelines.

Quality health care is family-centered,
community-based, coordinated, and
culturally competent.

-a Family Voices Principle

Family Voices of Nevada

www.familytiesnv.org



MARCIA O'MALLEY

Family TIES of Nevada
3100 Mill St, Suite #117
Reno, NV 89502-2217
Fax: (775) 448-9881

❖ (775) 823-9500
(866) 326-8437

❖ momalley@
familytiesnv.org



BUILDING PARTNERSHIPS: *Families and Policymakers*

Family TIES is hosting its 6th class of the Nevada Partners in Policymaking training, a group of 16 participants, 12 of whom are parents of CYSHCN, 1 a YSHCN, and 4 adults with disabilities. These individuals will join graduates (over 90 throughout the state) in efforts to improve the lives of all people with disabilities through active participation on committees, boards and advisory bodies.

"Trained consumers have a huge, positive impact on the system of service. This not only makes a difference in their lives, but in the lives of many others."

- Director of
Partners in Policy Making,
1998 – 2002



Family Voices of Nevada at Family TIES engages families and professionals in a number of ways to promote quality health care services for CYSHCN. These include assistance provided through individual support, training, parent matching, support groups, conferences, topical calls, surveys, website, video, and resource guides. Funding to support these activities is provided by a CMS F2F grant, Champions for Progress Incentive Award, and a sub-grant from the Nevada State Health Division.

2006 HIGHLIGHT: *Expanding Training Opportunities*

FV of Nevada at Family TIES, in partnership with the Nevada Bureau of Family Services, is developing an on-line training center to enhance the web-based resources for its Family-to-Family Health Information and Education Center. Two courses will be offered later this year: "Understanding Olmstead" and "Nevada Youth Health Transition Training." They anticipate a number of families and professionals who previously could not attend their face-to-face workshops will be able to participate in this new self-paced, on-line educational opportunity.

BUILDING PARTNERSHIPS: *Transition*

Last year, FV of Nevada at Family TIES hosted the "**Nevada Youth Health Transition Training**" to educate youth, family members and medical professionals about transitioning youth with special health care needs from pediatric to adult services.

"I learned (again) how important it is to prepare adolescents to participate in their health care. . . to support their parents, . . . and to expect health care providers to include children and adolescents in their own health care by talking with them and listening to them, not addressing everything directly to the parent/guardian."

- a provider

WORKING TOGETHER FOR CYSHCN:

FV of Nevada at Family TIES partners with many organizations, including:

- Maternal and Child Health Coalition
- Nevada Covering Kids and Families Coalition
- Hidden Miracles Hispanic Support Group
- EPSDT Parent Support and Education Workgroup
- Nevada Interagency Coordinating Council
- Latinos United Celebrating Health (LUCES)
- Nevada's Aging and Disability Resource Center Project
- Nevada 2-1-1 Partnership
- Nevada University Center for Excellence in Disabilities
- Nevada Governor's Council on Developmental Disabilities
- Nevada Disability Advocacy Law Center
- Nevada Bureau of Family Health Services, CSHCN Program
- Northern Nevada Center for Independent Living

Family Voices of New Hampshire

www.nhfv.org



TERRI OHLSON-MARTIN
MARTHA-JEAN MADISON

29 Hazen Drive
Concord, NH 03301
Fax: (603) 271-4902

❖ (800) 352-3345 x.4525(NH)
(603) 271-4525

❖ nhfv@yahoo.com



ADVOCACY IN ACTION:

In 2006, FV NH:

- Distributed almost 9,000 newsletters
- Informed over 900 families and professionals by participating in 163 meetings
- Distributed over 50,000 materials developed to assist families in raising their children with SHCN.



BUILDING PARTNERSHIPS: *Family Leadership*

NHFV provided assistance in over 1,000 instances in 2006 to families and the professionals that serve them, often focusing on navigating health care delivery systems.

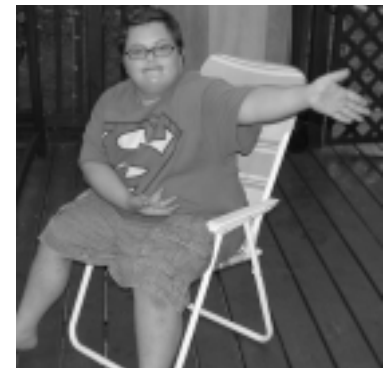
"It was great to meet and talk with you at the resource fair Tuesday. You were tremendously helpful in supporting and guiding my next steps."

- a parent

New Hampshire Family Voices (NHFV) is a parent-run organization that provides information and supports to families of children and youth with special healthcare needs (CYSHCN) and the professionals that serve them. NHFV provides this assistance through direct contact (telephone, e-mail, in-person), publication development and dissemination, workshops, trainings, and presentations as well as partnership activities with state agencies and community-based organizations. NHFV receives funding from Title V, CMS, the Hood Center for Family Support and a Champions grant.

2006 HIGHLIGHT: *Focus on Training*

A key project area in 2006 has been the development of a training program to help families create a "Child Profile" health plan that promotes integration of their child with special healthcare needs in everyday settings such as daycare, recreational opportunities, dance class, and others. By bringing a positive healthplan to community settings this 'child profile' helps to diminish fears and bring about successful participation. The promotion of strong emergency plans has also been part of this initiative.



WORKING TOGETHER FOR CYSHCN:

NHFV continues to outreach and partner with community based services throughout the state and has seen utilization of NHFV increase in all regions, with a significant increase in the North Country. Collaborative activities have included:

- Working with NH Healthy Kids and DHHS, Medicaid Client Services and NH Title V, CSHCN Program in identifying families of CYSHCN and making sure they are linked to available services and resources,
- Working with NH Title V, CSHCN Program, Special Medical Services and the Center for Medical Home Improvement (CMHI), in developing a brochure for families, "Does Your Child with Special Health Care Needs Have a Medical Home? - Learning more about this new way of thinking about primary care..."
- Working with the Concord Hospital Special Needs Committee, in creating a "Spica Cast Care" booklet for families, tips from parents for parents to help in managing the many weeks of having a child in a cast.

Family Voices of New Jersey

www.spannj.org/familywrap/
familyvoices.htm



DIANA AUTIN

NJ SPAN
35 Halsey St., 4th Floor
Newark, NJ 07102
Fax: (602) 242-4306

❖ (973) 642-8100 x.105

❖ diana.autin@
spannj.org



BUILDING PARTNERSHIPS: *Families and Providers*

SPAN NJ has provided the 'family perspective' to 50 organizations/work groups through representation at over 250 meetings, participation in a dozen statewide conferences, and participation in numerous discussions with state and federal agencies and policy makers. SPAN NJ has partnered with many organizations including:

- ❖ Disability Budget Coalition
- ❖ NJ Immigration Policy Network
- ❖ EPSDT Medicaid Workgroup
- ❖ American Academy of Pediatrics Committee on Children with Disabilities
- ❖ Healthy Care Advisory Committee
- ❖ Covering Kids and Families Coalition
- ❖ Mainstreaming Medical Care Advisory Committee
- ❖ National Family Caregivers Association
- ❖ Consumer Advisory Committees of several HMOs

Family Voices of New Jersey at Statewide Parent Advocacy Network (FV-NJ@SPAN) follows the SPAN motto "Empowered Parents: Educated, Engaged, Effective!" All of FV-NJ@SPAN activities focus on assisting families to partner in decision making for their children as well as at the policy level. Their surveys indicate that over 90% of families served are more knowledgeable about and confident in partnering with professionals on behalf of their children, and have used information from FV-NJ@SPAN to secure more appropriate services and better outcomes for their children. FV-NJ@SPAN provides assistance to families of CYSHCN in many ways, including: conferences, listservs and web based information, parent matching, newsletters, and meetings and trainings on a host of topics including, but not limited to, partnering, parent advocacy, health care policy and medical home.

2006 HIGHLIGHT: *Focus on Underserved Populations*

FV-NJ@SPAN receives funding from various sources to target diverse, underserved populations, including families of children receiving early intervention services, families of children who are deaf or deaf-blind, and immigrant families of children with special needs. A series of regional and statewide leadership activities are building the capacity of families to advocate for their own children and in public policy initiatives. Participating families have already positively impacted the proposed family cost share changes to early intervention as well as proposed changes to the state's SCHIP program.

"Imagine how it feels, the day you find out that your child has a significant disability. Imagine how alone, lost and scared a parent can feel... with no previous experience, with no guidance... Imagine a language barrier and cultural issues on top of all of the above. That's where SPAN's parent support comes in. My support parent was the light I needed when I was stuck in the tunnel of the unknown fogged by emotions. ...she held my hand through the tunnel!"

- a parent

WORKING TOGETHER FOR CYSHCN:

FV-NJ @ SPAN has been very involved with other partners in activities focusing on all 6 core outcomes for CYSHCN, including:

- ☑ **Medical Home:** Focusing on asthma, AIDS, immunization, obesity, and prevention of child abuse with partners AAP-NJ and NJ Title V office.
- ☑ **Screening:** Collaborating on newborn hearing screening activities with the EPSDT Workgroup, Early Intervention outreach workgroup, and the NJ Title V agency.
- ☑ **Community-Based Services:** Collaborating with the NJ Hospital Association & the NJ Immigration Policy Network to make hospitals and clinics more accessible to immigrant families.
- ☑ **Family Participation:** Providing leadership development to diverse parents to strengthen their capacity to impact public policy.
- ☑ **Transition:** Development of a searchable, interactive CD—From Back Seat to Driver: Roadmap to Transition to Adult Life; working with state on regional Dare to Dream Student Leadership conferences.

**Family Voices of
New Mexico**



PATRICIA HOLMES

261 Calle don Santiago
Los Lunas, NM 87031

❖ (505) 865-7483

❖ lyndara@comcast.net

RACHAEL SANCHEZ

1034 HWY 313
Bernalillo, NM 87004
Fax: (505) 867-3314

❖ (505) 553-5704
(505) 771-5403

❖ RaSanchez@salud.unm.edu

DAVID MURCHIO

Brain Injury Association of NM
121 Cardenas NE
Albuquerque, NM 87108
Fax: (505) 271-8983

❖ (505) 292-7414
(888) 292-7415

❖ dmurchio@msn.com



**WORKING TOGETHER FOR
CYSHCN:**

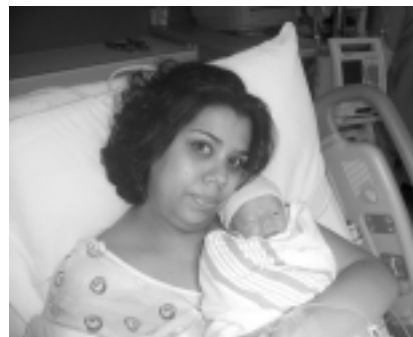
In the 2007 Legislative Session the Family-to-Family Health Information Center in collaboration with other non-profit and state agencies successfully advocated for:

- ❖ full funding for Medicaid;
- ❖ hearing aid coverage under Medicaid for children and adults;
- ❖ a mandate for private insurers to provide hearing aid coverage.

Family Voices of New Mexico (FV of NM) provides health information and supports families of CYSHCN and the professionals who serve them in many different ways: individualized support, parent matching, focus and support groups, conferences, training, resource guides, lending library, listserv, newsletters, and website. This assistance is supported with funding from CMS (Family-to-Family Health Information Center), Title V Children’s Medical Services, Molina Healthcare, and Lovelace Health System.

2006 HIGHLIGHT: EPSDT

The Family-to-Family Health Information Center of New Mexico was extremely successful in assisting the State of New Mexico with the implementation of the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program. 1915(c)



Waivers in New Mexico traditionally provided medical services to children with special health care needs. In July of 2006 medical services were no longer going to be provided to children from birth to age 21 under the waiver, which meant that these families would need to begin receiving services through EPSDT. The Family-to-Family Health Information Center was effective in advocating for equal rates for

services to children with special health care needs, with the result that EPSDT recipients could access services and supports with the same provider rates as those served through waivers.

**BUILDING PARTNERSHIPS:
Leadership Development**

FV of NM helps families in New Mexico provide critical information and insight in state and local agencies about services and supports that affect children with special health care needs.

“I never knew how effective my voice could be until I began to participate on a committee. I was finally able to use my experience of having a child with special needs to help others.”

- a family member

Families practice cost-effectiveness and expect the same from our health systems and services.

-a Family Voices Principle

Family Voices of New York



RUTH WALDEN

Family Voices NYS Liaison
 Department of Health
 Corning Tower Bldg Room 208
 Albany, NY 12237-0618
 Fax: (518) 474-3914

- ❖ (518) 474-0570
- ❖ rxw03@health.state.ny.us



ADVOCACY IN ACTION:

In 2006, FV of NY participated in specific initiatives on topics including:

- Emergency care and services
- Medical Home
- Mental Health
- Transition to Adult Health Care
- Youth Leadership
- Quality Assurance



BUILDING PARTNERSHIPS: Youth and Providers

A working relationship involving Family Voices, the New York State Department of Health and youth and young adults within the state has highlighted true partnerships. The resulting Youth Advisory Committee will focus on several of the National Performance Measures, benefiting greatly from the input of youth.

Family Voices of New York (FV of NY) provides information and resources to families of children and youth with special health care needs (CYSHCN) and the professionals who work with them through individual information and referrals, parent matching, conferences and sharing of materials including care notebooks and resource guides. Continuing to work with families to promote leadership and advocacy has increased state membership and helped to introduce Family Voices to more families. FV of NY partners with Title V on the NY Title V Needs Assessment and Block Grant. Family Voices of New York has also provided education and training for pediatric residents, nurses and dentists.

2006 HIGHLIGHT: *Early Childhood Screening*

Family Voices is pleased to be a part of the Child Development Learning Collaborative for early childhood developmental screening, a very successful opportunity for working with families and pediatricians. The Child Development Learning Collaborative focuses on developmental screening and surveillance of young children. Each team consists of a pediatrician, a care coordinator and a family member who work on quality improvement activities surrounding surveillance and screening and quality improvement. Data collected supports the need for leadership development and information for families.

"Involving families makes all the sense in the world and now we have it."
 - a pediatrician

WORKING TOGETHER FOR CYSHCN:

Family Voices of NY partners with others on activities related to the 2010 Performance Measures:

- Family Participation:**
 - Helping families to learn skills for effective participation through NY CSHCN Program's Champions for Progress Training Opportunity
 - Participating on the AMCHP Family Leadership Caucus
 - Advising AMCHP Family/Youth Scholarship Program
- Medical Homes / Community-Based Services:**
 - Expanding the understanding and implementation of Medical Homes and community-based services in partnership with the NY State Department of Health, American Academy of Pediatrics State Chapter, and the Academy of Family Physicians-NY State Chapter.
 - Presentation at the Regional Emergency Medical Services for Children Meeting about Family Centered Care from pre-hospital providers and in the Emergency Department; participation on the EMSC Advisory Council.

Family Voices of North Carolina



GRACE SISCO

Exceptional Children's Assistance Ctr.
907 Barra Row, Suite 102/103
Davidson, NC 28036
Fax: (704) 892-5028

❖ (704) 892-1321 x.11

❖ gsisco@ecacmail.org

SAM BOWMAN

Mount Airy, NC 27030

❖ (505) 553-5704

(505) 771-5403

❖ vbowman@triad.rr.com

MARY STOUGH

Wilmington, NC 28405

❖ (910) 791-8219

❖ MaribytheC@aol.com

WENDY WARD

Exceptional Children's Assistance Ctr.
Davidson, NC 28036

❖ (704) 892-1321 x.35

(800) 962-6817

❖ HIC@ecacmail.org



ADVOCACY IN ACTION:

In 2006, FV of NC:

- Assisted families and professionals in response to nearly 8,000 requests
- Distributed 103,000 newsletters
- Informed over 3,600 families and professionals by participating in 191 meetings
- Distributed 2,138 family-friendly materials

Family Voices of North Carolina (FV of NC) is a program of the Exceptional Children's Assistance Center (ECAC). FV of NC is a "beacon" for families of CYSHCN offering support and information, including conferences, listservs, newsletters, direct one-on-one support, work shops and training, and lending library. Funding for these activities has come from a CMS Family-to-Family grant and will continue with a grant from MCHB, ECAC's discretionary funds, and training contracts with the Children and Youth Branch NC State Division of Health (Title V).

2006 HIGHLIGHT: *Family-to-Family Health Information & Support*

With the goal of increasing family members' ability to partner in decision-making around health care for their CYSHCN, FV of NC hired a full-time Lead Parent Educator in 2006. This effort has resulted in:

- * Six new information packets for families:
 - ❖ Public Health Programs 1 (Medicaid, Medicare, EPSDT, SSI,)
 - ❖ Public Health Programs 2 (Local Health Department Clinics and programs),
 - ❖ Health Consumer Rights and Related Laws,
 - ❖ Private Health Insurance
 - ❖ Patient Assistance Programs
 - ❖ Medical Home Training
- * Two Project brochures (also in Spanish)
- * Development of Training Teams of community agencies across the state
- * Increased participation in agency and parent networks
- * Electronic newsletter, "The Beacon", and articles in ECAC's "Newslines"



BUILDING PARTNERSHIPS: *Focus on Family Leadership*

FV of NC participates in a variety of activities to promote family leadership:

- State Title V Family Council
- Title V Block Grant Review
- Title V Needs Assessment
- Medical Home Initiative Work Group
- Transition Work Group for the Office of Health and Disability
- Kindergarten Health Assessment Work Group

Family Voices of North Dakota

www.fvnd.org



DONENE FEIST

P.O. Box 163
Edgeley, ND
Fax: (701) 493-2635

❖ (701) 493-2634

❖ fvnd@drtel.net

TWYLA BOHL

4075 Sixty-Fifth St NE
Knox, ND 58343
Fax: (701) 252-4697

❖ (701) 583-2591

❖ twylabohl@hotmail.com



"Family Voices of North Dakota has done a wonderful job of helping families get involved in testifying to the lawmakers, and I think that has directly improved some services. We currently are having issues...for our child and that is very difficult...but without the involvement of FVND, we wouldn't have a clue as to where to turn."

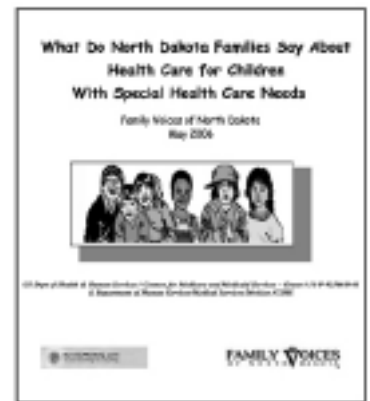
- a survey respondent



Family Voices of North Dakota (FVND) assists families of CYSHCN and the professionals who serve them as a Family-to-Family Health Information Center funded by CMS. This assistance is provided in many ways, including individualized information and referral, focus groups, parent matching, conferences, care notebook and resource guides, lending library, listserv, website, and a weekly e-newsletter, Share the Wealth. In addition to these services, FVND works closely with the state legislature and agencies to help improve programs for CYSHCN.

2006 HIGHLIGHT: *Giving a Voice to Families*

In May, 2006, FVND conducted an electronic survey of 90 families to identify health and service experiences of families of CYSHCN in North Dakota. Families were asked about their understanding of their child's health care program, the care their child receives and their relationship with their child's doctor(s). In addition, the survey obtained feedback from families on their areas of concerns, needed improvements and other suggestions. Some highlights from survey respondents:



- * 46% did not feel at all comfortable or felt somewhat comfortable with their knowledge of health care financing programs
- * 41% did not feel at all satisfied or felt somewhat satisfied with the quality of primary care, obtaining referrals & appointments for needed services and coordination among both primary and specialty care
- * 32% did not feel at all satisfied or felt somewhat satisfied with the level of input and involvement when working with their child's primary care provider

FVND is sharing this report with key stakeholders as well as expanding its dissemination of information about the areas of need reported by families

WORKING TOGETHER FOR CYSHCN:

FVND partners with many other organizations to improve care for CYSHCN, including:

- Medicaid Pediatric Task Force
- Medical Home State Team
- ND Disabilities Advocacy Consortium
- Robert Wood Johnson 'Covering Kids' Advisory Board
- Children's Special Health Services Family Advisory Council
- Early Childhood Alliance Advisory and Early Childhood Alliance State Team

Family Voices of Ohio



CAROL KELTNER

1111 Edwin C. Moses Blvd.
Dayton, OH 45408
Fax: (937) 208-8373

❖ (937) 208-7547

❖ chkeltner@mvh.org



BUILDING PARTNERSHIPS: Youth and Providers

This past year, FV OH developed relationships with children's hospitals in the state. Three major hospitals expressed interest in housing experienced parents in their Family Resource Centers. The idea of locating several parent navigators throughout the state allows for the creation of services that are truly community-based. FV Ohio will continue to work tirelessly to find funding for this collaborative project.



Family Voices of Ohio (FV OH) activities focus on assisting families to partner in decision making for their children and at the policy level. FV OH provides assistance to families of CYSHCN in many ways, including: parent matches and support groups; and printed and web based information, including care notebooks, family surveys and newsletters. Through a variety of activities, FV OH addresses youth and family leadership, early intervention and EPSDT, Special Education, transition to adult services, cultural competence, disaster planning and emergency care, and public and private health care financing.

2006 HIGHLIGHT: *EPSDT*

In Ohio, Medicaid revision of an EPSDT rule remains under discussion. Several Family Voices parents provided testimony during the year, sharing how proposed changes, especially taking 'habilitation' services out of EPSDT wording would significantly impact the services their children would be eligible to receive.

"There is no way my son, who has quadriplegic cerebral palsy, could be attending and succeeding at Wright State University if he did not have intensive quality therapies throughout his childhood."

- a parent

"How can you say my baby can only have rehabilitative therapy? She can't be 'rehabbed' if she never had the ability in the first place."

- a parent

FV OH brought this issue to the attention of many advocacy groups, supported families in providing testimony, and will continue to work with families to be sure their voices are heard on this issue of critical importance to Ohio families of CYSHCN.

WORKING TOGETHER FOR CYSHCN:

FV OH partnered with Voices for Ohio's Children, a non-partisan, resourceful, and popular group of organizations and individuals interested in improving the well-being of our community's children and their families. Family Voices Ohio participated in the Steering Committee that identified an agenda of 6 key areas for how Ohio can best invest in our children. FV Ohio was particularly vocal in defining the needs of families of children with special health care needs under the key area of Child and Family Health. Collaborating with Voices for Ohio's Children and with the state's Title V CSHCN program has had a positive impact on FV Ohio.

Family Voices of Oklahoma



LYN THORESON LAND

2311 Apache NW
Piedmont, OK 73078
Fax: (515) 243-1902

❖ (405) 202-3984

❖ LynT@health.ok.gov

TRACI L. CASTLES

University of Oklahoma
801 NE 13th St
Oklahoma City, OK
Fax: (405) 271-2432

❖ (405) 271-2131 x.47135



"I have used the information from the Family Voices of Oklahoma newsletter on several occasions.... Families ... are inundated with information from the Internet, support groups and various other entities. It can be very difficult for these families to know who or what to believe.

Family Voices of Oklahoma is a reliable source of information that helps our families make informed decisions when facing educational or medical choices for their child. I appreciate that Family Voices of Oklahoma is a reliable resource for our families."

- Family Services
Coordinator for
SoonerStart, Oklahoma's
Early Intervention program

Family Voices of Oklahoma (FV Oklahoma) helps families and professionals work together to improve the quality of health care services for CYSHCN in Oklahoma. This assistance is offered through the dissemination of information and resources through newsletters, surveys, and websites.

2006 HIGHLIGHT: *Focus on Family Partnerships*

FV Oklahoma continues to work toward getting information to families and increasing partnerships throughout the state. FV Oklahoma has a partnership with Statewide Training and Regional Supports

(STARS), a training program at the University of Oklahoma Health Sciences Center/Tolbert Center for

Developmental Disabilities. The mission of STARS is to support the provision of individualized, comprehensive, multidisciplinary, family-centered, community-based programs and services for people with disabilities through a coordinated statewide training system. In the past, families were not aware of the opportunities available through STARS. FV Oklahoma is now distributing the STARS training information through a quarterly newsletter so that more families will have the opportunity to attend STARS trainings.



BUILDING PARTNERSHIPS: *Diverse Communities*

Oklahoma's Latino population is growing by leaps and bounds. This year, the OK MAMAs support group in central Oklahoma learned about Family Voices. On two occasions in 2006, Forty-five families who all have young children with disabilities received the Family Voices in Oklahoma newsletter in Spanish. The majority of these families are living in poverty and do not have the resources or time to access information from the Internet or public library. FV Oklahoma celebrates this new partnership and looks forward to providing quality health care, parenting and educational information to Latino families in their native language.



Family Voices of Oregon



BECKY ADELMANN

5118 SW Lowell St
Portland, OR 97221
Fax: (503) 494-6868

❖ (503) 494-7657

❖ adelmann@ohsu.edu



BUILDING PARTNERSHIPS:
Families and Policymakers

FV OR has been working with other advocacy organizations on health care reform issues in the state legislature. Efforts include participating in meetings with legislators and policy makers, as well as giving testimony on bills related to Medicaid buy-in for families, expanded health care for children, and a waiver for medically needy children. This legislative session is important for many Oregon families who lack insurance, have insurance that doesn't pay for what they need, and cannot get the supports they need to keep children in their own homes.



Family Voices of Oregon (FV OR) provides assistance to families and professionals as they work together to improve outcomes for CYSHCN in Oregon. FV OR engages in such activities as individual support, information and resource sharing, educational presentations and training, and partnership with agency and family organizations. Activities are supported through partnerships and funding from CMS for development of the Oregon Family-to-Family Health Information and Education Center.

2006 HIGHLIGHT: *Building Capacity*

Family Voices of Oregon is developing its Family-to-Family Health Information and Education Center, and has recently reapplied for additional funding. This initiative is an important opportunity to assist parents and caregivers with the information and support they need for their children and families. Parents have reported difficulty in accessing complex health care systems and getting information in meaningful ways. This effort honors the skill and expertise of veteran parents who can assist other family members to successfully navigate systems of care.

BUILDING PARTNERSHIPS: *Families & Community-Based Services*

FV OR works closely with many organizations to both include and support families in their activities. Some of these activities are:

- With the Oregon Center for Children and Youth with Special Needs and its Family Involvement Network to include families on its community based teams and in its program planning and evaluation.
- With Disability Compass, to provide information for a web based resource database for people with disabilities and families. This is a great statewide resource that will provide a variety of resources and connections for families that will help them find services and information they need.
- Partnership with Oregon Family Support Network on issues related to children's mental health
- Collaboration with the Western State Genetics Collaborative to incorporate family perspectives in planning and evaluating genetic services.

Quality health care is family-centered,
community-based, coordinated,
and culturally competent.

-a Family Voices Principle

Family Voices of Pennsylvania



SUE BADEAU

30 Pelham Road
Philadelphia, PA 19119
Fax: (215) 844-3536

❖ (215) 844-6641
❖ sbadeau@aol.com

SHEILA DONNELLY

655 Bardwell Road
Factoryville, PA 18419

❖ (570) 836-7319
❖ sheilaamandad@yahoo.com



ADVOCACY IN ACTION: *Leadership Training*

In 2006, FV PA participated in the Parents with Special Needs Committee to provide resources, training and other supports for parents with special needs who are parenting children with special needs.



Family Voices of Pennsylvania (FV PA) shares resources with families of CYSHCN through a variety of activities including one-to-one contacts with family members, focus groups, conferences and listservs. FV PA works with other organizations to ensure that parents have information on family and youth leadership, legislative advocacy, special education, Medical Home, mental health, cultural competence, foster care services, transition to adult care and vocational rehabilitation.

2006 HIGHLIGHT: *Impact of Trauma*

FV PA has been active in an initiative to help parents and practitioners (medical, social work, mental health and others) understand the impact of trauma on children's development, and how to best intervene with children who have special needs AND have been impacted by trauma as a result of abuse, neglect, or other circumstances. FV PA has also worked to address transition needs and services for youth with special health care needs transitioning into adulthood, particularly youth who also have other challenges such as foster care placement.

BUILDING PARTNERSHIPS: *Special Needs Task Force*

FV PA continues to provide the family perspective while serving as a parent representative on the PA Department of Public Health Special Needs Task Force, a group that counts among its membership representatives of the state Medicaid agency, SCHIP program, Title V agency, private hospitals, medical practices and insurers, advocacy organizations, schools and other stakeholders. As a member of this task force, FV PA has led workshops and training sessions for social workers, program executives, medical practitioners and parents.



**Family Voices of
Puerto Rico**



MARIA de L. FERNANDEZ

PO Box 9023793
San Juan, PR 00902-3793
Fax: (787) 724-5780

- ❖ (787) 722-6334
- ❖ fedzargote@prtc.net

IRLANDA RUIZ

PO Box 367003
San Juan, PR 00936-7003

- ❖ (787) 281-8600
- ❖ iruiz@serpr.org



ADVOCACY IN ACTION:

In 2006, FVPR:

- ☑ Provided assistance to 1,142 families & 136 professionals on the island
- ☑ Hosted 60 meetings with 3,964 total participants
- ☑ Averaged 1,550 members on their listserv



**BUILDING PARTNERSHIPS:
Families and Policymakers**

FVPR, with other parent organizations, hosted its annual conference, "Segundo Foro Juridico sobre los Derechos de las Personas con Impedimentos in San Juan," bringing together families, legislators, advocates, and speakers from the island and the states.

Family Voices of Puerto Rico (FVPR) helps families of CYSHCN by providing them with information, resources and support through a variety of activities including individual information and referral, support groups, trainings, conferences and newsletters. Over the last year, FVPR has worked closely with other parent led organizations on the island, like the Autism Foundation, the Title V program, early intervention programs, the Department of Education, Head Start, Protection and Advocacy, Foster Care, private insurance companies and others to be sure families have information about early intervention and screening, education, health care services and financing, respite, transition to adult health care, disability specific information and information on advocating for their children.

2006 HIGHLIGHT: Training and Support for Emerging Parent Leaders

FVPR met with parents across the island to explore available programs and services and determine what is needed for children and youth with special needs. FVPR partnered with Bayamon County to establish an early intervention program and a program for children with Autism. Parents of children with disabilities and/or special health care needs were part of the Paraprofessional Training hosted by FVPR in 2006. A parent board, selected by FV and other parent organizations and made up of parents from throughout Puerto Rico, was part of every training. Parents had the opportunity to give input into which topics and speakers would be included in the trainings.

WORKING TOGETHER FOR CYSHCN:

FVPR has met with some of the most recognized family organizations and important agencies in Puerto Rico:

- Comité Timon (Consent Decree Group)
- APNI, Inc (Puerto Rico's Parent Training and Information Center)
- all groups supporting persons with autism
- COPAVNI
- Department of Education
- Puerto Rico Bar Association



to be sure that parents are "at the table" when issues regarding their CYSHCN's health and education are being discussed.

Family Voices of Rhode Island

www.ripin.org/fvri.html



DAWN WARDYGA

175 Main Street
Pawtucket, RI 02860
Fax: (401) 727-4040

- ❖ (401) 727-4144 x.158
- ❖ (800) 464-3399 x.158 (RI)
- ❖ familyvoices@ripin.org

BARBARA TORRES

175 Main Street
Pawtucket, RI 02860
Fax: (401) 727-4040

- ❖ (401) 727-4144 x.161
- ❖ (800) 464-3399 x.161 (RI)
- ❖ torres@ripin.org



ADVOCACY IN ACTION:

In 2006, FV RI:

- Provided assistance to families & professionals in over 600 instances
- Distributed over 37,000 newsletters
- Participated in 408 meetings attended by over 894 family members & professionals



Family Voices at the RI Parent Information Network (FV/RIPIN) provides information, advocacy, education and support to families and advocates at the local, state, and national level to improve quality in the programs that serve children and youth and their families. The assistance provided by FV/RIPIN to families and professionals is offered through a broad system of communication: through individual support, conferences, focus and support groups, parent matching, training, topical calls, and information disseminated through website, listservs, newsletters, and other materials. These activities are funded by Title V and CMS (F2F HIEC Grant) with additional funding support from Neighborhood Health Plan of RI, the Rhode Island Children and Families Trust Fund, and UnitedHealthcare, Inc.

2006 HIGHLIGHT: *Building Parent / Professional Partnerships*

FV/RIPIN, in partnership with the RI Department of Health – Office of Special Healthcare Needs and Neighborhood Health Plan of RI, hosted its 3rd annual family/professional partnerships conference in June. Attended by more than 140 parents and professionals caring for children and youth with special health care needs, the conference, “Partnerships: Communities Supporting Children and Youth with Special Health Care Needs” covered such topics as:

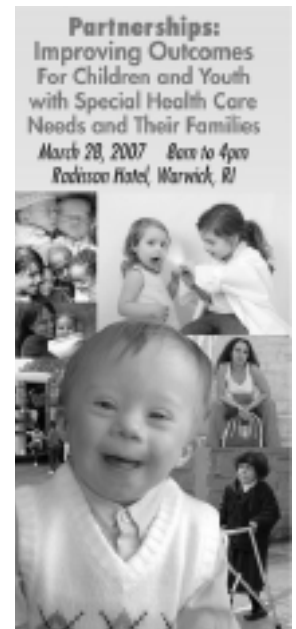
- * The President's New Freedom Initiative,
- * Screening: Newborn & Early Childhood Development,
- * Partnerships at Work in Educational Systems,
- * Partnerships Addressing Autism Spectrum Disorders,
- * Community-Based Services for CYSHCN,
- * Family Support Opportunities,
- * Trends in Health Care Financing,
- * Adolescent to Adult Transition,
- * Partnerships at Work in Primary Care, and
- * Project DOCC - a medical education program.

This conference was a great opportunity for families and professionals to educate, inform, and build partnerships in caring for children with special health care needs.

WORKING TOGETHER FOR CYSHCN:

Highlights of FV/RIPIN Partnership work with others includes:

- Working with Maternal and Child Health Coalition
- Working with Medicaid agency on Leadership Roundtable for CYSHCN
- Advising on the state's Rite Care/Rite Share and other Medicaid programs
- Collaborating with Title V on most initiatives
- Assisting Neighborhood Health Plan of RI and UnitedHealthcare in efforts to improve services for CYSHCN.



Family Voices of South Carolina

www.familyconnectionsc.org



PAT HEAD

Family Connection
2712 Middleburg Dr, Suite 103B
Columbia, SC 29204
Fax: (803) 799-8017

❖ (803) 252-0914
(800) 578-8750 (SC)

❖ pathead@familyconnectionsc.org



WORKING TOGETHER FOR CYSHCN:

Family Connection, in its role as the state's family-to-family network and as SC Family Voices organization, supports a family liaison who receives inquiries from parents with CYSHCN and provides needed information and advocacy to assist them in choosing health plans available through Medicaid. Family Connection works collaboratively with SCDHHS and managed care companies to assure that CYSHCN are receiving care in a timely manner. They are at the table to assist in increasing knowledge about families with CYSHCN, inform about Medicaid eligibility programs, and assist in the eligibility process, as well as to promote medical homes, EPSDT, training for providers serving CYSHCN, and to institutionalize the role of parent/family support.



South Carolina Family Voices (SCFV), housed at Family Connection, a support network for families who have children with special needs, provides assistance to families and professionals through a broad system of programs and services, including:

- * individualized support
- * support groups
- * parent matching
- * training
- * focus groups
- * conferences
- * lending library
- * resource guides
- * care notebook
- * videos
- * topical calls
- * listservs
- * newsletters
- * website
- * surveys

This work is supported by funding from governmental contracts, private donations, grants, foundations, and fundraising.

2006 HIGHLIGHT: *Partnering with Policymakers / Legislators*

During the 2006 session of the South Carolina General Assembly, SCFV and other parent advocates organized a grassroots initiative seeking new legislation that would require insurance companies to provide coverage for the treatment of Pervasive Developmental Disorder (PDD) and to define PDD as a neurological condition related to Autism and Asperger's Syndrome. "Ryan's Law," as it was named, would have enabled young children in SC in need of therapies to access them through private insurance. As a compromise to both help families and hold insurance companies harmless, the 2006 General Assembly appropriated \$3 million to be matched by Medicaid funds to develop a PDD pilot program. The project will treat children who have been diagnosed with PDD by 8 years of age. Treatment for each child may not exceed 3 years and reimbursement for each child may not exceed \$50,000 per year. Ryan's Law will be re-introduced during the 2007 General Assembly.

BUILDING PARTNERSHIPS: *Families and Communities*

SCFV and Family Connection provide invaluable help to families of CYSHCN as they learn to navigate complex health care service systems:

"Family Connection has not only afforded us much help throughout the years as parents of a child who has a disability, but also equipped us to be an effective conduit to help others. Early on, the systems regarding disability can be quite confusing for a parent. For us, we did not know where to turn to receive important information and resources concerning our daughter. Family Connection staff made themselves available and gave empowering and invaluable information concerning what was available in the areas of healthcare, education, and recreational opportunities. I had the opportunity to attend the support parent training at Family Connection. Being a support parent has allowed me to form real friendships where we support and learn from each other. Family Connection also continues to be a tremendous resource of information that enables us to advocate effectively for my daughter and others with disabilities on the local, state, and national level."

- a parent

Family Voices of South Dakota

www.familyvoicessd.org/home.shtml



DINA CASTRO

3701 W. 49th, Suite 102
Sioux Falls, SD 57106
Fax: (605) 361-2928

❖ (605) 361-3171
(800) 640-4553

❖ dcastro@sdparent.org



ADVOCACY IN ACTION:

In 2006, FV SD:

- ☑ Received 4,650 calls from both parents and professionals
- ☑ Distributed information in over 5,000 newsletters
- ☑ Informed just over 19,000 families and professionals by participating in 653 meetings
- ☑ Disseminated over 20,000 written materials



"The information I received in the mail after our phone conversation was excellent...It really is much easier to work with professionals when you know what you are talking about."

- a parent



Family Voices of South Dakota (FV SD) is one of six programs under the umbrella of South Dakota Parent Connection (SDPC) and is an important component



in helping SDPC advocate for CYSHCN. SDPC's goal is to empower families and professionals with information and knowledge, including referrals related to health care and/or educational concerns. SDPC provides support, parent and mentor linking, a variety of trainings, a lending library, resource guides, and a quarterly newsletter. These activities are supported with funding from CMS (F2F grant), Federal Department of Education (PTI grant), State Department of Health (P2P grant), and State Department of Special Education.

2006 HIGHLIGHT: *Partnerships to Shape Policy*

FV SD partnered with several organizations including The Catalyst Center, SD Voices for Children and the SD Medicaid Program to develop a formula that each state could use in order to implement funding for the Family Opportunity Act (FOA). SD was one of the first states to propose the new FOA legislation at the state level. Efforts on the part of FV SD helped to ensure that the FOA would be part of the 2007 legislative session. Although the legislation did not pass, these groups will continue to work during the interim to help educate policymakers as to the importance of this legislation.



BUILDING PARTNERSHIPS: *Families, Title V, Other Organizations*

FV SD works closely with the SD Title V program and, as a result, families are consistently and meaningfully included in state activities and are given opportunities to provide input into future plans that affect families of CYSHCN. Title V values the family perspective and brings families to the table to help guide improvements to health care programs and services. SD FV also partners with other organizations in this effort:

- SD Parent Connection
- SD Advocacy
- SD Voices for Children
- SD Family Support Program
- Center for Disabilities
- Children's Care Hospital & School
- Universal Pediatric Services
- SD Department of Education
- Southeastern Behavioral Health
- SD Department of Social Services

Family Voices of Tennessee

www.tndisability.org/familyvoices/



JULIE SULLIVAN

2465 Bybee Chapel Rd
Rock Island, TN 38581
Fax: (931) 686-3810

❖ (931) 686-3353

❖ fvtn@tndisability.org

DONNA GRAHAM

330 Brittontown Rd
Afton, TN 37616
Fax: (423) 234-2449

❖ (423) 234-2334

❖ familyvoices@
tndisability.org



WORKING TOGETHER FOR CYSHCN:

Through a partnership with the TN Title V program and Vanderbilt University, FV Tennessee has developed and mailed a comprehensive family survey to 7,000 Title V and FV families in the state. The responses promise to provide important information about the needs and experiences of families, help state agencies in setting priorities for improving services for CYSHCN within the state, and provide evidence of the value of partnerships between universities, Title V and family organizations.



Family Voices of Tennessee (FV Tennessee) provides information and support to families as they navigate health care systems in Tennessee as well as to the professionals who serve families. This assistance is provided in a variety of ways, including: individual information and referral, support and focus groups, training, parent matching, conferences, topical calls, listservs, newsletters, surveys, and website. FV Tennessee is funded by a number of grants: an F2F grant from MCHB, a LEND grant through a Vanderbilt University contract, a grant from the TN Department of Health, a State Improvement grant from the TN Department of Education and funding from the TN Disability Coalition.

2006 HIGHLIGHT: *Building Capacity to Serve Families*

During 2006, FV Tennessee added 3 part-time parent consultants in east, middle, and west Tennessee to their team. Each is a parent of a child with hearing loss and they provide information and support to other families through our contract with the TN Department of Health's Universal Newborn Hearing Screening Program. It is the first time there has been a coordinated statewide family network to assist and serve as a resource for these families.



West TN parent consultant Wonda Houston, Middle TN parent consultant Teresa Turnbo, East TN parent consultant Camille Keck

BUILDING PARTNERSHIPS: *Families & Providers*

For a number of years, FV Tennessee has provided leadership on family centered care for the LEND interdisciplinary leadership training program coordinated by the Vanderbilt University Medical Center. In 2006, a parent of a CSHCN was enrolled as a trainee at the graduate level representing family as a discipline for the first time.

"My experience with the LEND/MIND program has been so enlightening. I truly can see the MD and other professionals' position more clearly, whereas before, I only saw them as the messenger. I now see them as people, who more often than not, are striving to provide the best treatment they believe will help my or someone else's child. It has also been very empowering to have a voice at the table of higher education professionals to speak to the experiences of being a parent of a CSHCN. The blending of professionals and families in this program is a perfect partnership to train upcoming medical and social services professionals."

- a parent

Family Voices of Texas

www.txp2p.org
www.thehaliproject.org/



BRAD THOMPSON

The HALI Project, Inc.
26551 Newton
Canyon, TX 79015
Fax: (806) 352-5698

❖ (806) 352-5647

❖ bthompson@southwest.org

LAURA WARREN

Texas Parent to Parent
3710 Cedar St. Box 12
Austin, TX 78705
Fax: (512) 451-3110

❖ (512) 458-8600
(866) 896-6001 (TX)

❖ laura@txp2p.org

ELAINE HIME

University of Houston
210 Student Services Center 1
Houston, TX 77204-3025
Fax: (713) 743-5383

❖ (713) 743-5435

❖ ehime@mail.uh.edu

MARY KLENTZMAN

P.O. Box 3724
Temple, TX 76502
Fax: (254) 778-6785

❖ (254) 770-2353

❖ mklentzman@
special-children.org



Family Voices of Texas (FV of TX), through a collaborative network of community-based parent organizations, provides assistance to the many families across the great state of Texas. Through the work of The HALI Project and Texas Parent to Parent (TxP2P), families and state agencies are beginning to find ways to partner together to improve services for CYSHCN. These organizations also provide specific services to families, including:

- | | | |
|--------------------------|-------------------|-----------------|
| * individualized support | * conferences | * topical calls |
| * support groups | * lending library | * listservs |
| * parent matching | * videos | * newsletters |
| * training | * resource guides | * website |

This assistance is supported with funding from CMS (TxP2P F2F grant), Texas Council for Developmental Disabilities grant, contracts through the Department of Assistive and Rehabilitative Services (Division of Early Childhood Intervention & Children with Special Health Care Needs), and contracts for private counseling/education.

2006 HIGHLIGHT: *Families and Providers*

TxP2P has a Medical Education Program in which parents serve as Family Faculty to train pediatric and family practice residents in four hospitals in Texas. This program has opened the eyes of future doctors in understanding the role of the family in health care for CYSHCN. Participating residents indicate that they are able to apply the knowledge they've gained from this program in their clinical practices. Important benefits are also realized by the participating family members who learn new skills to partner with their own physicians.

WORKING TOGETHER FOR CYSHCN: *Building Medical Homes*

Both TxP2P and The Hali Project are actively involved in Medical Home Initiatives:

- sharing the family perspective through participation on the Parent Advisory Committee
- partnering with a primary care provider in Amarillo as a pilot CareShare site
- partnering with the Medical Home Work Group (Title V – CSHCN) to create and disseminate the Medical Home Toolkit (500 copies in a 6-month period).

"The Medical Home Toolkit truly helped me understand the concept of Medical Home."

- A doctor serving on the Medical Home Work Group

Family Voices of Utah



GINA POLA-MONEY

Utah Family Voices at the
Utah Parent Center
2290 East 4500 South #170
Salt Lake City, UT 84117
Fax: (801) 565-1695

❖ (801) 808-4220
(800) 468-1160 (UT)
❖ utahfamilyvoices@
juno.com



BUILDING PARTNERSHIPS: *Families and Policymakers*

Utah Family Voices has been added to the on-going curriculum of the University of Utah School of Medicine, Department of Pediatrics, the School of Physical Therapy and the School of Nursing to present on the family perspective and family-centered care. Through these efforts and partnerships they are able to expand the philosophy of true family professional partnerships and Medical Home. Utah Family Voices and the Utah Parent Center provide examples of care notebooks, emergency information forms and disability resources books that can be used to highlight family roles and expand family expertise.



Utah Family Voices (UT FV), through the Family-to-Family Health Information, Education and Support Center, provides a broad range of assistance to families and professionals. This includes individualized information and referral, focus and support groups, parent matching, training, topical calls, conferences, care notebook and resource guides, listserv, surveys, website, and a newsletter. These activities are supported with funding from CMS (F2F grant), The Utah Parent Center, Title V/Children with Special Health Care Needs Bureau, Utah State University (LEND grant), Utah Regional Leadership Education in Neurodevelopmental Disabilities, and Utah Integrated Services Project.

2006 HIGHLIGHT: *Early Intervention*

Utah Family Voices has been very involved with Early Intervention. Through this partnership they have helped to coordinate efforts of families, educating policy-makers through their personal family stories, and emphasizing the importance of the vital services of Early Intervention services statewide. Through these efforts families have made their voices heard and emphasized sustaining funding as a top priority.



BUILDING PARTNERSHIPS: *Developing Family Leadership*

Through efforts of the Utah Family Voices Health Information Center, the Utah Regional Leadership Education in Neurodevelopment Disabilities project and the Utah Collaborative Medical Home Project, the number of families who are equal partners in activities and who are compensated for their expertise and experience has increased.

"I had been struggling to get a therapy through Medicaid that was denied. After talking with Utah Family Voices I was able to appeal and learn about EPSDT and medical necessity. Utah Family Voices provided information on medical necessity that my providers were able to use and get the therapy approved. I feel more at ease knowing that getting a denial is not the end, there is a way to get them to look at what my child needs."

- a parent

Family Voices of Vermont

www.partoparvt.org/fv.html



KAY VAN WOERT

207 Spinnaker Lane
Shelburne, VT 05482
Fax: (802) 985-2539

❖ (806) 352-5647

❖ kvanwoert@aol.com

HILARY MELTON

600 Blair Park Rd, Suite 240
Williston, VT 05495-7549
Fax: (802) 764-5297

❖ (802) 764-5290 x.19
❖ (800) 800-4005 x.19 (VT)

❖ hilary.melton@
partoparvt.org

JULIE AREL

600 Blair Park Rd, Suite 240
Williston, VT 05495-7549
Fax: (802) 764-5297

❖ (802) 764-5290 x.16

❖ julie.arel@partoparvt.org



BUILDING PARTNERSHIPS:

Families and Providers

FV@P2PVT has fostered family participation and provided a family perspective in work with:

- ❖ VT State Legislature
- ❖ VT Dept of Health
- ❖ VT Children with Special Health Needs Program
- ❖ VT Dept of Disability, Aging, and Independent Living
- ❖ VT Dept Children and Families
- ❖ Catalyst Center
- ❖ Medicaid Advisory Board and Consumer subcommittee
- ❖ VT Coalition for Disability Rights
- ❖ VT Parent Information Center
- ❖ VT Building Bright Futures Council and Parent Committee
- ❖ Early Childhood Systems Grant

Family Voices at Parent-To-Parent of Vermont (FV@P2P-VT) is a multi-faceted organization with a 20 year history of serving families throughout Vermont. Assistance is provided to families and professionals in many ways:

- | | | |
|--------------------------|-------------------|---------------|
| * individualized support | * conferences | * surveys |
| * support groups | * lending library | * listservs |
| * parent matching | * videos | * newsletters |
| * training | * resource guides | * website |

These services are funded by a Family-to-Family grant from MCHB and support from Title V, private foundation funding, Medicaid match, and donations.

2006 HIGHLIGHT: Focus on Health Care Financing

After significant increases in premiums for the past few years, FV@P2P-VT worked hard with partners and families to focus state debate on health care financing. As a result, Medicaid and SCHIP premiums for children were reduced by half, and the EPSDT benefits under a new Global Commitment Medicaid funding system were protected. FV@P2P-VT also took leadership that achieved significant increases in respite funding and program improvements in the children's personal care services programs. This will increase access to health care for many children throughout Vermont.

BUILDING PARTNERSHIPS: Developing Family Leadership

FV@P2P-VT helps families become partners through a continuum of activities:

- Families, matched with one of 350 trained support parents, gain help and education and frequently go on to become supporting parents themselves.
- Through a Family Faculty program, families are trained to be teachers about family-centered care for future healthcare providers, including medical students, pediatric residents, speech-language students and physical therapy students
- Parents learn to become vocal and active participants in policy making

"I've taken my story before the legislature. I've gone to people high up in certain organizations on my child's behalf to make people understand the issues. I don't know where I'd be without them (FV@P2P-VT) quite frankly. They've empowered me over the years to become the strong advocate I am today."

- a family member

Family Voices of Virginia



MAUREEN MITCHELL

12617 Thunder Chase Drive
Reston, VA 20191

❖ (202) 494-8383

❖ va_familyvoices@yahoo.com

STACY JUSTISS

31722 Government Road
Damascus, VA 24236

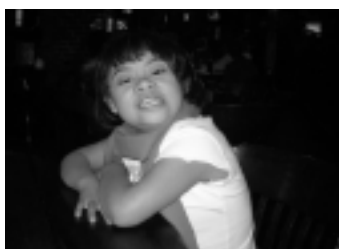
❖ (276) 475-6525

❖ stacyjustiss@msn.com



**ADVOCACY IN ACTION:
*Family Support***

The following is an example of effective support that FV of VA provides on an ongoing basis to the families of Virginia. A mother had tried for two years to obtain Medicaid waivers for her two adopted children. After receiving one-to-one support from FV of VA, including information specific to the application process, this mother was able to more effectively navigate the system, and within 3 months obtained a waiver to provide in home personal assistance for her children.



Family Voices of Virginia (FV of VA) widely disseminates information and resources to families of CYSHCN and the providers who serve them, through meetings and workshops, conferences, direct support, and parent matching. FV of VA has been part of the funded F2F HIC in VA serving families throughout the state, participating in conferences, meetings, material development and information dissemination.

2006 HIGHLIGHT: *Training and Support for Emerging Parent Leaders*

At a statewide conference in July 2006, FV of VA developed a workshop on how to negotiate systems of care, and helped participants identify barriers to services and specific methods for successfully navigating these systems. Parents from throughout the state had an opportunity to connect during this workshop. Those interested in helping other parents to access information and resources or becoming more involved in systems change, had the chance to sign up to receive information from FV of VA for their own personal use and to assist them and others as they work to improve services to CYSHCN in their communities.

BUILDING PARTNERSHIPS: *Families and 2010 Performance Measures*

FV of VA has been very involved with partners working together on activities focused on the core outcomes for CYSHCN, including:

- ☑ **Family Participation:**
 - Working closely with Medical Home Plus, Inc., sharing a family’s perspective on the medical home concept through visiting pediatric practices involved in a medical home improvement project
- ☑ **Medical Homes / Community-Based Services:**
 - Collaborating with Parent-to-Parent of VA on a presentation and workshop on “Parent Involvement”
 - Serving on the Fairfax Region CCC Advisory Committee and serving as co-chair on the Parent-to-Parent Support subcommittee.

WORKING TOGETHER FOR CYSHCN:

FV of VA collaborates with many parent led organizations in VA:

- Parent Education and Training Information Center
- The Arc
- Title V: Care Connections for Children
- Waiver Network
- State Dept of Education
- Dept of Mental Health and Mental Retardation
- VA INFO Coalition made up of over 100 members serving families of CYSHCN

Family Voices of Washington



CASSIE JOHNSTON

6138 Waldon Dr SE
Olympia, WA 98513
Fax: (253) 566-8052

❖ (253) 566-2266

❖ weecare@olywa.net



BUILDING PARTNERSHIPS: Families and Policymakers

FV WA is active in bringing family perspective to the policy process, including supporting recent successful legislation to expand health care access to all children and to ensure that they have a medical home. This new legislation will expand health coverage, consolidating several health coverage programs into a single unified program. All children will have comprehensive coverage, regardless of income or citizenship status. Benefits are comprehensive: medical, dental, vision and mental health.



Family Voices of Washington (FV WA), provides assistance to families to help them navigate health care systems for CYSHCN in Washington. This assistance is provided through several venues: individual information and support, trainings, and information disseminated through newsletters, listservs, surveys and websites. These activities are supported with funding from the US Department of Education (IDEA Part C) and CMS (F2F grant).

2006 HIGHLIGHT: Focus on Health Care Financing

FV WA has moved forward in the last year in partnership with the Washington State Family-to-Family Network in the implementation of the Family-to-Family Health Information Center. The WA Family-to-Family Network is made up of:

- * Families of Children with Special Health Care Needs,
- * Washington Children with Special Health Care Needs Program,
- * Washington Infant Toddler Early Intervention Program,
- * Washington State Fathers Network,
- * Washington State Medical Home Program,
- * Washington State Parent-to Parent Programs,
- * Parent Support at Children’s Hospital
- * Washington PAVE.

“I have learned many new things about Children with Special Health Care Needs that help my grandson and others who have family members with children with special health care needs. Being an advocate for a special needs child is not an easy job and it takes a family and information to do the best job you can for that child. Family Voices of Washington has helped me become involved with planning the Family-to-Family and getting information for my grandson with special needs.”

- family advisory board member for Family Voices of Washington

FV WA has implemented a listserv and is sharing information on health and wellness for children with special health care needs. Numerous aspects of outreach and training are in development to ensure partnerships and the inclusion of the family voice from diverse communities.



Family Voices of

Wisconsin

www.wfv.org/fv/



LINDA ROWLEY

PO Box 226
Mineral Point, WI 53565

❖ (608) 263-5973

❖ linda@fvofwi.org

LIZ HECHT

1483 Sunrise Lane
Belleville, WI 53508
Fax: (608) 265-3441

❖ (608) 239-1363

❖ liz@fvofwi.org

BARBARA KATZ

PO Box 55029
Madison, WI 53705

❖ (608) 233-3726

❖ barb@fvofwi.org



ADVOCACY IN ACTION:
Leadership Development

Family Voices of WI's network of Parent Trainers have trained more than 100 parents and providers statewide using the "Did You Know? Now You Know!" curriculum. These training modules offer participants fundamental information on accessing and navigating health care and community supports for CYSHCN.



Family Voices of Wisconsin (FV WI) with support from both WI Title V and a CMS funded Family-to-Family Health Information Center grant, provides assistance to families of CYSHCN and providers who support them. A cornerstone of Family Voice's activities is the "Did You Know? Now You Know!" training, offered statewide with a network of parent trainers. Family Voices assists families to access needed information and supports and become involved in systems changes through participation in focus groups, topical calls, a listserv, website, and training. Family Voices also published a newsletter that was disseminated to over 3,800 individuals in 2006. Family Voices has a number of products including a web-based resource guide and a report on effectively engaging parents from minority groups in leadership roles and enhanced decision making.

2006 HIGHLIGHT: Supporting Family Leaders

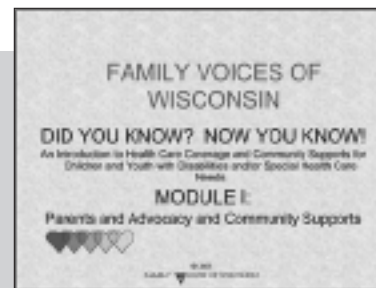
Last summer, FV WI sponsored a retreat for parent leaders. This day of reflection, rejuvenation and connection brought together parents who participate in leadership and partnership activities in the areas of education, healthcare, and community supports. All of the parents who attended serve on numerous councils and committees as parent representatives and the retreat allowed them to think about ways in which they could strengthen their roles as partners.

"I was thrilled to have had the opportunity to connect with other parent partners and learn from one another. I am so glad that Family Voices brought us together."
-a retreat participant

WORKING TOGETHER FOR CYSHCN:

FV WI is involved in many initiatives, including:

- Providing newsletters and a listserv to inform and connect families to information and opportunities for involvement.
- Co-sponsoring the Annual Medical Home Summit with the WI Title V program, the WI Chapter of the AAP and the WI Academy of Family Practitioners
- Supporting the Survival Coalition of Wisconsin Disability Organizations' legislative agenda of ensuring that people with disabilities receive the services and supports they need to live their lives as they wish and be full participants in community life.
- Addressing the extensive waiting lists for community services for children.
- Supporting the development of a KASA group in Wisconsin.



Family Voices of Wyoming

<http://health.groups.yahoo.com/group/familyvoicesofwyoming/>



RICK SKAGEN

504 Hancock St
Laramie, WY 82072

❖ (307) 745-6875
❖ (800) 681-1423 (WY)

❖ U2Dreambig@aol.com



ADVOCACY IN ACTION:

In 2006, FV of WY:

- Distributed 500 newsletters
- Engaged 75 individuals by listserv
- Informed over 220 families and professionals by participating in 7 meetings
- Provided information and assistance on the following topics:
 - ❖ Advocacy
 - ❖ Health Care Financing
 - ❖ Respite
 - ❖ Medical Homes
 - ❖ Community Resources
 - ❖ Disabilities
 - ❖ Education



Family Voices of Wyoming (FV WY) helps families of CYSHCN by offering support, guidance, information and referral to those who are just learning the extent of their children’s special health care needs. FV WY connects families to a support system of other experienced families so that they will have a source of help as they learn to navigate the road ahead. FV WY offers support groups, conferences, listserv, newsletters, and a care notebook. These activities are provided, in a large part, by volunteer effort – almost 600 hours logged by Network Coordinator, Rick Skagen, in 2006.

2006 HIGHLIGHT: *Focus on Health Care Financing*

FV WY has partnered with the state to develop a Medical Home Notebook, available by download from the WY State Department of Health website and in printed form by request. This resource has been very helpful to both families and professionals as they work to coordinate medical care for CYSHCN. FV WY also distributes a newsletter from the WY State Department of Health.



BUILDING PARTNERSHIPS: *Developing Family Leadership*

FV WY has recently attained a small grant from the Wyoming Governor's Planning Council for Developmental Disabilities that focuses on advocacy training through Partners in Policy Making. This is a great opportunity for families to receive training in how to contact their legislatures and how to advocate for their families/children. FV WY continues to offer other workshops and conference trainings.



KASA

www.fvkasa.org



*Representing the voice
of youth living with disabilities
and chronic health conditions*



JULIE SIPCHEN, Project Director

❖ julie@fvkasa.org

NAOMI ORTIZ, Project Coordinator

❖ naomiortiz01@msn.com

❖ (888) 835-5669



NATIONAL ADVISORY BOARD

Micah Fialka-Feldman
Jen Halpert
Samantha Henault
Sarah Ingerson
Jennifer Thomas
Heidi Fletcher
Shanea Blount
Rajiv Root
Chad Murphy-Price
Matthew Potter

TASK FORCE

Micah Fialka-Feldman
Eleanor Bailey
Natalie Burdick
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Tyler Greene
Lyndsi Holmes
Matthew Potter

KASA is an initiative that promotes and improves the lives of youth with disabilities and chronic health conditions through informing youth about their rights, facilitating peer-to-peer support, and promoting systems change to include youth perspective.



KASA provides technical assistance to youth, their adult allies and organizations around transition and policy issues and the development of youth led initiatives, and disseminates materials and information to promote youth perspectives. These activities are supported by a grant from the ACF/Administration on Developmental

Disabilities and the MCHB NCFPP cooperative agreement.

2006 HIGHLIGHT: *Rethinking Standardized Testing & Exit Exams*

In the past few years, exit exams have been added to the regimen of standardized testing for high school students. While used as a tool for states to improve education practices, exit exams are controversial as they have become a requirement for graduation. **KASA** has examined the development of exit exams and has chosen “to speak out in order to influence those in power to listen and act as allies in creating change” to systems that effect youth with disabilities. With input from youth around the country, the **KASA** Task Force has written a white paper, “Standardized Testing: What Youth with Disabilities Have to Say.” This report:

“It [standardized tests] can have serious effects on the lives of people with disabilities despite the fact that they are not necessarily designed with us in mind”
-High school student from Florida

- * Discusses the problems with testing as identified by young people
- * Examines how standardized testing has historically impacted people with disabilities, and
- * Makes recommendations on how to improve test accessibility and knowledge of rights.

This white paper will be available shortly. For more information, visit the **KASA** website, www.fvkasa.org.

BUILDING PARTNERSHIPS: *Developing Youth Leadership*

One of the ways KASA pursues its vision of leadership development is through the KASA Task Force. This group of younger youth, ages 13-18, meets monthly by conference call to connect with one another, to learn about key issues and the connections between their work on a local/national level and the larger disability community. Calls generally focus on a specific topic and often include presentations by subject-matter experts. Some of the topics this year have included:

- Policy Issues for Youth
- National Disability Rights Network
- Jerry's Orphans
- School to work transition
- ADAPT

WORKING TOGETHER FOR YOUTH: *Building a Vision*

An exciting project is in the works for creating space for youth/young adult voice and leadership. KASA has representation in a group of disability community leaders, called the **Disability Activist Collective**. One of their projects is to develop, launch and analyze a survey of disabled youth and adults to learn more about what people want for the future of the disability community. They will present the results of the survey in the form of a vision statement for the future of the disability rights movement at the National Council on Independent Living (NCIL) conference in July.

Presenting at NCIL is just the beginning! They look forward to working with the disability community in the future to continue the process of developing values of the disability community and vision for the future.

This survey and vision statement will set ground-breaking **direction for the future of KASA, other youth groups, and their partners** as they develop plans to meet the needs of youth in the future.



KASA and the National Youth Leadership Network (NYLN) have collaborated on the development of three new documents:

- * Respectful Disability Language: Here's What's Up!
- * Accessibility and Accommodations: Making opportunity accessible to all
- * Accessibility Checklist: Information for Everyone?

KASA and NYLN will discuss these at the Administration on Developmental Disability Technical Assistance Institute in August. In addition, they will co-present "*Working Together to Speak Out*", an examination of the lessons, successes, and challenges of their partnership experience together.

KASA PUBLICATIONS

Available at

Youth Leadership Manual, a 25-page "how-to" manual on including youth as leaders in your organization, agency or project.

KASA Brochure, their vision, their value, their future.

Fact Sheets and Tip Sheets:

- ❖ Advocacy Tips
- ❖ What is Self Determination?
- ❖ Medical Model vs Social Model of Disability
- ❖ Disability Community Resource List
- ❖ How to do a Job Search
- ❖ Getting a Job: Building your Interview Skills
- ❖ Your Rights at the Dr's Office
- ❖ Keeping Track of your Health Care Information
- ❖ Role & Responsibility of Voc Rehab Services
- ❖ Advocating in Middle & High School
- ❖ Solving a Problem so Everyone is Happy
- ❖ How to Run your IEP
- ❖ How to Get Into College
- ❖ Staying Healthy
- ❖ How to Lead a Focus Group
- ❖ And more at www.fvkasa.org



VIDEO:

**Through the Same Door:
*Inclusion Includes College***



This inspiring film documents the new movement of fully inclusive education by exploring **KASA Board member Micah Fialka-Feldman's** desire for a life without boundaries. To learn more about this award winning DVD or view a clip from the movie, go to www.throughthesamedoor.com.

Requests Received for Assistance



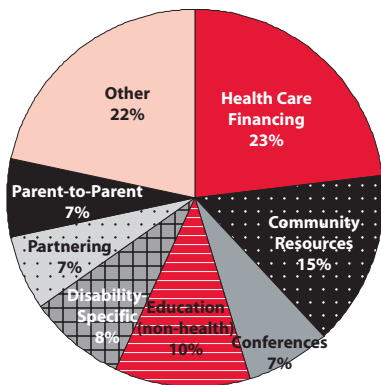
Avg # of contacts per family: **2.17**

Avg # of contacts per professional: **2.25**

Avg % of families served from underserved communities: **41%**



Topics of Information Provided



Family Voices, Inc. provides TA and support to F2F HICs and Family Voices Network Members to help them collect data reflecting work they do to assist families and professionals. As noted within this report, this work may be supported by multiple funding sources. Summarized below is information collected within the states, and aggregated by Family Voices for the period January – December 2006.

FAMILIES AND PROFESSIONALS REQUESTING ASSISTANCE:

Many families turn to F2F HICs and FV Network Members for assistance in finding and providing appropriate care for their children and youth with special health care needs. Professionals also seek assistance from family organizations in order to work more effectively with families, children and youth. In 2006, the submitting family organizations reported:

- * 64% requests for assistance from families (124,219)
- * 36% requests for assistance from professionals (70,271)

Examples of the kinds of requests received from families included finding payment for medical care, seeking to talk with another parent, or looking for help navigating public health care financing programs. Examples of requests received from professionals included seeking a family perspective on materials, identifying parents to serve on advisory committees, or looking for information to help a family find community resources.

Because of the complexity of medical needs and health care systems, families and professionals usually make contact with an F2F HIC or FV Network Member more than once in order to obtain the assistance they need. On average, families made 2.17 contacts to get the assistance they needed and professionals made 2.5

F2F HICs and FV Network Members estimated that, on average, 41% of the families they served were from traditionally underserved communities, including families from diverse ethnic and socio-economic backgrounds and geographic settings. Those submitting data reported a variety of methods to identify this demographic information including participant self-identification, asking specific demographic questions, census statistics, primary language spoken and information about geographic areas served.

INFORMATION AND ASSISTANCE PROVIDED:

In response to requests for assistance, staff at F2F HICs and FV Network Members provide many kinds of information to families and professionals, including helping parents understand a child’s disability, find and pay for services, and find emotional and other kinds of needed family support.

Information about health care financing was the most frequently reported type of assistance provided. Additional topics of information and assistance that were frequently provided include: community resources, conferences and workshops, education, disability-specific resources, partnerships, and parent-to-parent support. Other information topics reported include respite, oral health, transition, mental health, advocacy, medical home and screening.

ASSISTANCE WITH HEALTH CARE FINANCING:

Adequate health care financing is a critical component of quality care for a child or youth with special needs. Families seeking help from FV Network Members and F2F HICs reported nearly 21,044 problems related to health care financing.

- * 67% of the problems reported (14,296) were about public financing programs, such as Medicaid, SCHIP, Title V, and SSI.
- * 24% of the problems reported (4,956) were about health-related services in schools or early intervention programs.
- * 9% of the problems reported (1,792) were related to private insurance.

Examples of health care financing problems reported include limits in amount or duration of needed services, denials of referrals to specialists, denials of eligibility for programs, lack of providers, and waiting lists for programs and services.

PERFORMANCE MEASURES RELATED TO CYSHCN:

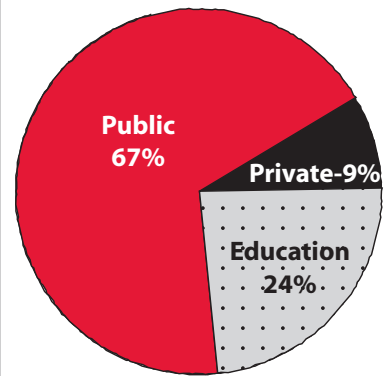
Six performance measures, designed to measure appropriate systems of health care for CYSHCN, were established as the result of the President’s New Freedom Initiative (2002). Researchers and policymakers are presently developing working definitions and measures that can be implemented by stakeholders in a meaningful and practical manner. For the Voices from Home 2006 report, Family Voices organizations were asked about the specific work they are doing around partnerships – both in helping families become partners in their children’s care, and helping families become partners at program and policy levels. The preceding pages provide a glimpse of the wide breadth of family activities underway to enhance partnerships and promote family-centered care. Family Voices Network Members were also asked to report on their involvement with community based services, transition, health care financing, Medical Home, screening and cultural competence. The adjacent chart indicates their replies. The average rating of all respondents in each area was more than 3.7 on a 5 point scale.

REACHING OUT TO FAMILIES AND PROFESSIONALS:

F2F HICs and FV Network Members share their expertise widely to impact systems and services that support families of CYSHCN

- * Almost **220 thousand individuals** were reached through **8,442 meetings** in which F2F HICs and FV Network Members participated.
- * Over **25.5 million website hits** were recorded on websites where F2F HICs and FV Network Members post materials.
- * Over **1.2 million newsletters** were distributed containing articles written by F2F HICs and FV Network Members.

Problems with Health Care Financing by Type of Program



Involvement in Activities related to Performance Measures

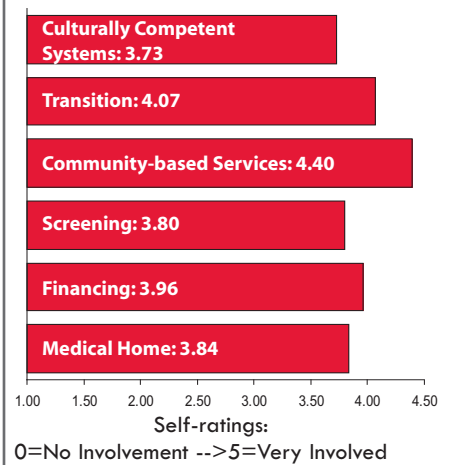


TABLE 1. TOPIC AREAS OF SPECIFIC INVOLVEMENT (NETWORK MEMBERS IN AL - NE):

State	AK	AL	AR	AZ	CA	CO	CT	DC	DE	FL	GA	HI	IA	IL	IN	KS	KY	LA	MA	MD	ME	MI	MN	MO	MS	MT	NC	ND	NE
Assistive Technology	•		•	•		•	•	•	•		•		•	•	•	•								•	•	•			
Autism	•		•	•	•	•		•	•		•	•		•	•	•		•		•	•			•	•	•		•	
Chronic Care Mgmt		•			•	•		•	•		•		•	•						•				•		•			
Cultural Competence		•	•	•	•		•	•		•	•	•	•	•	•			•		•	•	•			•			•	
Disaster Planning	•	•	•	•	•				•	•	•						•	•		•	•	•		•	•		•		
Domestic Violence							•											•			•			•					
Early Intervention	•	•	•	•	•	•	•	•	•			•	•	•	•	•		•	•	•	•	•	•		•	•	•	•	•
Electronic Health Records		•		•		•			•			•		•	•			•	•	•		•		•	•				
Emergency Care		•		•			•	•	•	•			•	•	•			•		•	•	•	•	•	•	•		•	
Family Leadership	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•			•	•	•	•	•	•	•	•	•	•	•
Foster Care							•	•	•		•			•	•					•				•	•	•			
Health & Wellness			•				•	•	•			•	•	•				•	•	•	•			•	•	•	•	•	•
Legislative Advocacy	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•		•		•	•			•	•	•		•	•
Medical Home	•	•	•	•	•	•	•		•	•	•	•		•	•			•	•	•	•	•	•	•	•	•	•	•	•
Mental Health	•	•	•	•	•	•	•	•	•	•	•		•	•	•	•		•		•	•	•		•	•	•	•		
Oral Health	•			•		•		•	•			•		•	•	•			•	•	•	•		•			•		
Palliative Care					•															•	•								
Parents w/ Disabilities			•			•	•	•			•	•	•	•	•	•		•		•	•	•		•	•				
Provider Education	•	•	•	•	•	•		•	•	•		•	•	•	•			•		•		•	•	•		•	•	•	•
Quality Assurance					•	•	•	•				•	•		•						•			•	•	•			
Respite		•	•			•	•	•	•		•	•	•	•	•	•	•			•	•	•			•			•	
Screening	•					•		•	•		•	•		•	•									•		•			•
Special Education	•		•	•		•	•	•			•	•	•	•	•	•	•	•		•	•	•	•	•		•	•	•	•
Subspecialty Care	•					•		•				•	•	•	•					•	•			•		•			
Transition		•	•	•		•	•		•		•	•	•	•	•	•		•		•	•	•	•	•	•	•	•	•	•
Voc Rehab		•	•			•					•	•	•	•	•	•		•		•			•		•		•		
Youth Leadership		•	•				•	•		•		•	•	•	•					•	•	•	•	•	•	•	•	•	•
Title V Needs Asmt	•	•	•	•		•	•		•			•		•		•		•		•	•	•	•	•	•	•	•	•	•
Title V Block Grant	•	•	•	•		•	•		•			•		•				•		•	•	•	•	•	•	•	•	•	•
EPSDT						•		•			•	•	•	•	•	•		•		•		•		•	•		•	•	•
Medicaid		•		•		•	•	•	•	•	•	•	•	•	•	•		•	•	•	•	•	•	•	•	•	•	•	•
Medicaid Buy-in		•	•	•		•	•				•	•	•	•	•			•		•	•			•	•		•	•	•
Medicaid Mng Care				•		•		•	•			•	•	•	•					•		•		•	•		•	•	•
Medicaid Waivers	•	•				•	•		•		•	•	•	•	•	•	•		•		•	•	•	•	•	•	•	•	•
Private Insurance				•		•	•	•				•	•	•	•			•		•		•	•	•	•	•	•	•	•
SCHIP		•		•		•		•				•		•	•	•			•		•	•	•	•	•	•		•	•
Self-directed Waiver						•			•		•	•	•	•	•					•					•		•		
Technology-dep Waiver						•						•	•	•	•														•

TABLE 2. TOPIC AREAS OF SPECIFIC INVOLVEMENT (NETWORK MEMBERS IN NH - WY):

State	NH	NJ	NM	NV	NY	OH ¹	OH ²	OK	OR	PA	PR	RI	SC	SD	TN	TX ¹	TX ²	UT	VA	VT	WA	WI	WY
Assistive Technology		•				•	•			•	•							•		•		•	•
Autism		•				•	•		•	•	•	•	•	•				•		•			
Chronic Care Mgmt		•					•		•	•		•	•					•	•	•			•
Cultural Competence		•				•	•	•	•	•			•	•	•			•		•			•
Disaster Planning			•			•	•							•	•			•				•	•
Domestic Violence													•	•									
Early Intervention	•	•				•	•	•				•	•		•	•	•	•	•	•	•	•	•
Electronic Health Records											•							•				•	•
Emergency Care	•		•		•	•	•								•			•					
Family Leadership	•	•		•	•	•	•		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Foster Care	•	•				•	•			•		•	•	•									•
Health & Wellness		•			•			•	•				•					•	•	•	•		
Legislative Advocacy	•	•	•	•		•	•	•	•	•	•	•	•	•		•		•	•	•	•	•	•
Medical Home	•	•			•	•	•		•	•		•	•	•		•	•	•	•	•	•	•	•
Mental Health	•	•			•		•	•	•	•		•							•	•			•
Oral Health	•											•	•					•	•		•		
Palliative Care																•		•					
Parents w/ Disabilities			•	•		•	•			•	•			•		•		•			•		•
Provider Education	•	•	•	•	•	•	•		•	•		•	•	•	•	•		•		•		•	
Quality Assurance		•			•		•				•		•					•					
Respite	•	•	•			•	•					•	•	•	•	•	•	•	•	•	•		•
Screening		•				•	•	•	•						•			•	•	•			
Special Education	•	•	•	•	•	•	•			•	•	•	•	•	•	•	•	•	•	•	•	•	•
Subspecialty Care	•				•				•				•					•	•	•			
Transition	•	•		•	•	•	•		•	•				•	•	•		•		•	•	•	•
Voc Rehab		•			•					•				•					•	•	•	•	
Youth Leadership		•		•	•	•	•		•	•			•					•	•			•	•
Title V Needs Asmt		•			•				•			•			•			•	•	•		•	
Title V Block Grant	•	•			•		•	•	•			•	•	•				•	•	•	•	•	•
EPSDT	•	•	•	•		•	•					•	•	•				•	•	•		•	
Medicaid	•	•	•	•	•				•		•	•	•	•		•		•	•	•		•	
Medicaid Buy-in		•	•	•	•	•	•		•				•				•						
Medicaid Mng Care		•	•	•		•	•		•			•	•			•		•	•	•		•	
Medicaid Waivers	•	•	•	•	•		•		•			•	•	•	•	•		•	•	•		•	
Private Insurance	•	•	•	•		•			•			•	•	•		•		•	•			•	
SCHIP	•	•	•	•		•	•		•			•	•	•		•		•	•	•		•	
Self-directed Waiver			•		•	•	•									•		•					
Technology-dep Waiver																		•		•			

¹OH-Bachmann, ²OH-Kelter, ¹TX-Thompson, ²TX-Warren

TABLE 3. PARTNERSHIP INVOLVEMENT (NETWORK MEMBERS IN AL - NE):

In order to assist other Network Members in developing partnerships, Network Members were asked to qualify their involvement with 32 organizations, some of which were specific and some categorized. This information in this chart is provided to encourage and facilitate mentorship within the Family Voices network in specific arenas of partnership development and should not be construed as evaluative.

1=No Involvement --> 5=Significant Involvement

State	AK	AL	AR	AZ	CA	CO	CT	DC	DE	FL	GA	HI	IA	IL	IN	KS	KY	LA	MA	MD	ME	MI	MN	MO	MS	MT
Medicaid Agency	2	4	2	5	3	5	3	3	5	5	5	5	5	4	3	2	3	5	3	5	3	5	5	1	4	2
SCHIP Pgm	2	4	1	5	2	4	4	3	3	1	3	5	1	2	2	2	1	2	3	4	4	4	2	2	3	2
360 Grantees	5	2	1	1	1	3	2	4	1	1	3	5	5	5			1	3	1			1		1	1	1
State Title V Pgms	5	5	5	5	5	5	5	3	5	5	3	5	1	5	3	5	5	5	3	5	5	5	5	5	3	3
Integrated Systems Grantees			1	5	5	3		1	1	1	3	5	1	4	4		1	2			5	2	5	3	1	1
Developmental Disability Agency	5	4	5	5	5	5	4	3	5	3	5	5	5	5	4	5	3	2	1	5	5	5	2	5	3	5
SSI	1	3	1	1	1	5	2	1	2	1	5	3	1	3	3	4	1	3	4	3	1	4	1	1	4	2
Indian Health Svcs	2		1	5	3	1	1	1	1	1	3	1	1	1			1	2	1	1	2	2	2	1	2	2
HMOs/Private Insurer	1		1	2	5	4	3	4	1	4	2	3	3	2	2		1	3	2	4	1	2	2	2	3	1
Health Care Advocacy Groups	4	5	4	5	5	5	4	5	5	5	5	3	1	5	5		4	5	4	5	5	2	3	5	3	5
Early Intervention Pgms	3	4	4	4	5	5	5	4	5	5	5	5	5	3	5	5	2	5	3	5	5	5	5	5	3	5
Dept of Education/Schools	5	3	5	5	5	3	4	5	3	5	5	3	4	3	5	5	2	4	1	4	5	5	4	5	4	5
Head Start	2	2	1	3	3	3	3	3	2	1	2	2	4	2	5	4	1	2		2	4	2	4	3	4	3
Mental Health Agency	4	4	3	5	3	4	5	3	2	5	4	2	3	2	3	5	3	5	3	5	5	5	3	5	4	4
Protection and Advocacy Agencies	4	4	5	2	5	5	4	5	3	3	5	5	1	2	2	5	2	2	1	4	3	2	3	4	4	5
Voc Rehab Agencies	2	4	5	3	3	4	2	2	2	3	5	3	3	2	2	5	2	3	2	4	1	5	4	2	3	3
Foster Care Agencies	2		1	3	3	3	5	5	2	1	5	2	1	2	2	5	2	2	1	2	3	2	4	3	3	2
Juvenile Justice Pgms	2		1	2	3	3	5	2	2	3	5	1	1	2	1		1	2	1	2	2	1	2	2	3	
State Chapter AAP	2	3	2	3	3	4	3	2	4	5	2	5	1	5	2		1	4	1	4	3	2	5	1	3	1
Children's Hospitals/Ped Units	5	4	5	5	5	5	5	3	4	3	2	3	2	3	5		1	5	5	4	4	2	5	5	3	5
Lend Pgm	4	4	2	1	4	1	5	2	1	1	2	5	5	5	2		1	3	4	5	3	1	1	2	1	3
P2P Pgms	5	5	2	5	5	5	4	4	1	3	5	3	5	3	5	5	2	4	4	4	5	5	4	5	3	5
PTI Pgms	5	4	5	5	5	4	3	1	2	4		3	5	3	5	5	3	4	1	5	5	5	5	3	4	5
Mental Health Orgs	4	4	4	3	3	5	5	3	2	5	2	2	4	5	4	5	1	5	3	4	4	5	2	1	1	3
Other Parent-led Groups	4	4	5	5	5	5	5		5	5	5	2	5	5	5	5	1	4	5	4	5	4	2	5	3	2
Disability-Specific Groups	1	4	5	4	4	5	5	3	5	4	5	2	2	5	5	5	2	5	3	4	5	2	3	5	3	5
Child Advocacy Orgs	2	4	5	5	4	5	5	4	2	5	5	5	3	3	5	5	1	4	2	4	5	2	3	5	3	4
March of Dimes	2	4	2	3	1	4	1	2	2	1	2	1	1	2	1		1	3	1		2	1	2	1	2	2
Youth Grps	1	3	1	3	5	2	3	3	2	3	5	2	5	2	2		2	4	4	2	5	2	4	5	2	5
Community Health/Rural Ctrs	2	3	1	3	5	4	1	2	3	2	5	2	1	5	3	3	1	4	1		2	2	2	3	2	2
Ethnic/Cultural Groups	2		3	5		4	2	3	2	5	2	1	5	3	1	3	1		1	5	2	5	2	4	2	2
Faith-based Groups	2	3	4	3	3	4	3	2	2	2	2	1	2	2	4		2	2	1	4	1	1	1	1	3	2

TABLE 4. PARTNERSHIP INVOLVEMENT (NETWORK MEMBERS IN NH - WY):

In order to assist other Network Members in developing partnerships, Network Members were asked to qualify their involvement with 32 organizations, some of which were specific and some categorized. This information in this chart is provided to encourage and facilitate mentorship within the Family Voices network in specific arenas of partnership development and should not be construed as evaluative.

1=No Involvement --> 5=Significant Involvement

State	NC	ND	NE	NH	NJ	NM	NV	NY	OH ¹	OH ²	OK	OR	PA	PR	RI	SC	SD	TN	TX ¹	TX ²	UT	VA	VT	WA	WI	WY
Medicaid Agency	3	5	5	4	5	5	5	3	5	5	1	3	4	3	5	5	3	2	3	1	5	4	5	1	2	1
SCHIP Pgm	4	5	2	4	5	4	5	3	3	5	1	3	2		3	4	3	2	1	1	3	2	5	1	2	1
360 Grantees		1	1	1	1	1	1	1	5	4	1		2	2	2	1	2	1	1	1	3	1	4	1	4	1
StateTitle V Pgms	5	5	5	4	5	2	5	5	5	5	1	5	4	4	5	4	5	2	5	4	5	5	5	4	5	1
Integrated Systems Grantees	3	5	1	5	3	2	5	5	5	4	1	5	3	3	2	4		2	1	4	5	2	5		5	1
Developmental Disability Agency	4	4	3	3	5	5	4	5	5	5	1	4	4	4	2	4	4	2	1	5	2	1	4	4	5	1
SSI	3	4	1	1	5	3	1	1	2	3	1	3	4	3	2	2	3	1	1	3	3	2	3	1	1	1
Indian Health Svcs	2	4	1	1	1	2	2	1	1	1	1	3	1	1	1	1	2	1	4	1	3	1	1	1	2	1
HMOs/Private Insurer	2	4	1	2	5	5	2	2	4	2	1	3	4	4	3	4	2	2	4	2	3	2	2		1	1
Health Care Advocacy Groups	4	5	1	2	5	5	5	4	5	3	1	5	5	3	5	4	4	4	3	4	4	5	5	3	3	4
Early Intervention Pgms	4	5	5	3	5	3	4	2	5	5	5	3	2	5	5	5	3	4	3	4	5	2	5	3	2	4
Dept of Education/Schools	4	5	5	2	5	3	3	2	5	4	1	1	5	5	2	4	5	5	3	5	3	3	3	1	4	4
Head Start	2	5	1	1	5	1	2	1	2	1	1	1	3	5	2	2	3	3	3	3	3	1	2	1	2	2
Mental Health Agency	4	4	1	1	5	2	2	4	2	2	5	4	5	4	3	1	3	5	1	3	2	3	4	3	1	3
Protection and Advocacy Agencies	3	5	1	2	5	5	4	2	4	4	2	3	3	4	3	3	5	1	2	4	2	1	3	1	5	3
Voc Rehab Agencies	3	3	1	1	5	2	2	2	3	4	1	1	4	3	1	1	3	1	2	3	2	1	3		3	1
Foster Care Agencies	3	3	1	3	5	1	2	1	2	3	1	1	5	4	4	1	3	1	2	3	2	1	3	3	1	4
Juvenile Justice Pgms	2	2	1	1	5	1	1	1	4	5	1	1	5	2	2	1	2	1	1	2	2	1	2	1	1	1
State Chapter AAP	3	5	4	1	5	1	1	3	3	4	1	5	1	2	4	4	2	2	2	2	5	3	4	3	3	1
Children's Hospitals/Ped Units	3	5	4	3	5	2	5	1	5	4	1	5	4	3	5	4	4	4	2	4	5	2	5	4	2	2
Lend Pgm	2	5	1	1	5	2	5	4	4	4	1	5	2	2	1	1	4	5	2	1	5	2	5	2	5	1
P2P Pgms	4	5	1	2	5	2	5	3	5	4	2		2	3	5	5	5	4	5	1	4	5	5	5	4	1
PTI Pgms	5	5	5	4	5	5	4	3	3	4	1	4	3	3	5	3	5	4	3	4	5	4	5	5	4	1
Mental Health Orgs	5	5	3	2	5	2	1	4	2	3	1	5	5	2	2	3	2	5	2	4	3	3	5	1	3	1
Other Parent-led Groups	4	5	4	3	5	2	5	2	3	4	4	4	5	5	4	3	2	4	4	5	4	3	5	5	3	3
Disability-Specific Groups	4	4	4	2	5	4	5	2	4	4	4	4	5	4	4	3	3	4	3	5	3	2	5	5	4	3
Child Advocacy Orgs	3	4	3	2	5	4	5	2	3	4	1	3	5		4	5	4	4	1	4	3	4	5	5	2	4
March of Dimes	3	3	3	1	3	2	3	1	3	4	1	2	1	4	4	5	3	2	1	2	3	1	3	1	1	1
Youth Grps	4	5	1	1	4	1	3	3	5	5	1	4	5	3	1	2	3	2	1	3	4	2	4	1	5	3
Community Health/Rural Ctrs	3	4	1	1	5	3	3	1	1		1	3	1	2	2	2	3	3	2	4	3	1	2	1	1	1
Ethnic/Cultural Groups	3	4	1	1	5	2	5	2	2	2	1	3	4	2	2	2	4	2	2	3	4	2	2	4	4	1
Faith-based Groups	2	2	1	1	4	2	1	1	1	2	1	2	5	1	2	3	2	2	3	5	2	2	2	1	1	1

¹OH-Bachmann, ²OH-Kelter, ¹TX-Thompson, ²TX-Warren

REGIONAL STRUCTURE

State Family Voices organizations are organized into regions aligned with the HRSA Maternal and Child Health Bureau Regions. Regional Coordinators are selected to help communicate information and share resources within and among regions and the Family Voices National Office.

Region 1:

Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont

Region 2:

New York, New Jersey, Puerto Rico, Virgin Islands

Region 3:

Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, West Virginia

Region 4:

Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee

Region 5:

Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin

Region 6:

Arkansas, Louisiana, Minnesota, New Mexico, Oklahoma, Texas

Region 7:

Iowa, Kansas, Missouri, Nebraska

Region 8:

Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming

Region 9:

Arizona, California, Hawaii, Nevada

Region 10:

Alaska, Idaho, Oregon, Washington

Brief Glossary of Terms

AAP - The American Academy of Pediatrics. www.aap.org

ARC - The Arc. Formerly Association for Retarded Citizens. www.thearc.org

Block Grants - The way the Federal Maternal & Child Health Bureau (MCHB) delivers funds to state programs.

CAHMI/Child and Health Measurement Initiative - CAMHI's mission is to ensure that children, youth and families are at the center of quality measurement and improvement efforts in order to advance a high quality consumer-centered health care system.

CDC/Center for Disease Control and Prevention - one of the operating components of the Department of Health and Human Services, CDC is charged with working to protect people's health and safety, provide reliable health information, and improve health through strong partnerships. CDC's mission is to promote health and quality of life by preventing and controlling disease, injury, and disability.

CMS/The Centers for Medicare and Medicaid Services - a federal agency within the U.S. Department of Health and Human Services that administers the Medicare program and works in partnership with the states

CSHCN/CYSHCN - Children (and youth) with special health care needs.

DDC - Developmental Disabilities Council, sometimes called the Governor's Council on Developmental Disabilities. The agency in each state authorized by the federal DD Act.

DHHS/Department of Health and Human Services - the United States government's principal agency for protecting the health of all Americans and providing essential human services. Many health-related agencies are housed within this department. Within each state, the state DHHS oversees the planning and administration of those services. Also called HHS.

EMSC/Emergency Medical Services for Children - EMSC is a national initiative designed to reduce child and youth disability and death due to severe illness and injury. A federal grant program supports state and local action. www.ems-c.org

EPSDT/Early Periodic Screening, Diagnosis, and Treatment - Mandatory Medicaid health benefits and services for Medicaid-eligible children and adolescents. Designed to ensure children's access to early and comprehensive preventive care and treatment. The state Medicaid agency is required to pay for and make sure that providers deliver EPSDT services.

F2FHIC/Family-to-Family Health Information Center - Run by and for families in each state, the vision for Family-to-Family Health Information Centers is to simplify the lives of families who have children with special health care needs and improve the health of children by: educating families about choosing health insurance and providers; guiding families to health resources; linking families, managed care programs, providers and policy makers; and developing partnerships at all levels of the health care delivery system.

HHS/Health and Human Services - See above DHHS.

HRSA/Health Resources and Services Administration – An agency of the U.S. Department of Health and Human Services, HRSA assures the availability of quality health care to low income, uninsured, isolated, vulnerable and special needs populations and meets their unique health care needs. www.hrsa.gov

GLOSSARY

ICC/Interagency Coordinating Council - In the federal government and in the states, this group plans and oversees Part C, the early childhood component of IDEA (see below). Its members represent many different agencies and must include a significant number of parents.

IDEA/Individuals with Disabilities Education Act - The federal special education law that describes and protects students with disabilities.

KASA/Kids As Self Advocates - KASA is a project of Family Voices, created by youth for youth to educate society about issues concerning youth with a wide spectrum of disabilities and special health care needs. www.fvkasa.org

LEND Program - Program from the Institute for Community Inclusion. Medical students participate as trainees working in Children's Hospital University Affiliated Program's (UAP) and learn about interdisciplinary leadership development. www.communityinclusion.com

Managed Care - A way to finance and deliver health care for a set fee using a defined network of services and providers. For information about managed care and children with special health care needs, ask for our free managed care brochure in English or Spanish. HMOs, Health Maintenance Organizations, are one form of managed care.

MCH/Maternal and Child Health - A program in every state that oversees and plans, and sometimes delivers health care and other services to infants, women, and children. At the federal level, these programs are overseen by MCHB/Maternal and Child Health Bureau, which is a bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services. www.mchb.hrsa.gov

Medicaid - The federal program that uses state and federal funds to provide health insurance for people who meet certain eligibility standards, including children.

Medicaid Waiver - Some Medicaid rules regarding income and other standards can be "waived" or dismissed in order to provide Medicaid coverage to certain groups of individuals, including children.

Medical Home - A care concept, strongly promoted by the AAP, which advocates, among other things, the medical care of infants, children, adolescents and young adults ideally should be accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective.

Medical Necessity - Legal term that determines what health services are provided and/or paid for.

Network member - The term Family Voices uses to describe the mostly volunteer Family Voices state coordinators and chapter representatives.

NICU/Neonatal Intensive Care Unit - also known as a newborn intensive care unit, is a specialized unit in hospitals designed to care for ill or premature newborn infants.

P2P/Parent-to-Parent - Parent-to-Parent programs provide emotional and informational support to parents of children who have special needs most often by matching families seeking support with an experienced, trained 'Supporting Parent'. While some states have statewide parent-to-parent networks, others do not. www.p2pusa.org

PTI/Parent Training and Information Centers - Family-run agencies funded by the federal Department of Education to provide education information and training to families who have students with special needs. Most states have at least one PTI.

Part C – Once called Part H, this term refers to the early childhood part of IDEA, the federal special education law.

SAMHSA/The Substance Abuse and Mental Health Services Administration – Within the US Department of Health and Human Services (HHS), SAMHSA works to improve the quality and availability of substance abuse prevention, addiction treatment, and mental health services.

SCHIP/ State Children’s Health Insurance Program - A federal law to use state and federal dollars to provide health insurance for uninsured children. Also known as Title XXI and CHIP.

SSI/ Supplemental Security Income - The Social Security Administration Children's SSI Program provides monthly cash benefits to certain individuals who qualify and requires that children pass strict disability and income standards.

Title V/CSHCN (Children with Special Health Care Needs) Program - Every state has an agency responsible for programs for children with special health care needs. The agencies have different names in each state, but all are referred to as Title V/CSHCN programs.