

2017 ACTIVITY HIGHLIGHTS

Family-to-Family Health Information Centers (F2Fs) | Family Voices State Affiliate Organizations (SAOs)

Family Voices is a family-led, nonprofit organization, working to keep families at the center of children's health care. Since forming Family Voices in 1992, families of children and youth with special health care needs have built a highly respected diverse national grassroots network of family and youth leaders focused on improving healthcare services and policies. The network of **Family Voices State Affiliate Organizations (SAOs)** and **Family-to-Family Health Information Centers (F2Fs)** in every state and DC provide information, assistance, and support to other families of children and youth with a range of special health care needs and/or disabilities and work closely with professionals to improve care. Their work and accomplishments are varied and extensive:

ALABAMA: Family Voices of Alabama and the F2F host an annual *Partners in Care Summit* each spring. A collaboration with Title V Children's Rehabilitation Service, The program brings in national speakers on issues for CYSHC to challenge and inspire those who attend from throughout the southeast. Summit themes have included Medical Home, Transition, and Advocacy.

ALASKA: Stone Soup Group convened a parent panel at the All Alaskan Pediatric Partnership Summit to speak directly to health care providers about the transition from pediatric to adult care. The protection and advocacy agency, Disability Law Center, participated to explain the legal ramifications as youth reach the age of majority.

ARIZONA: Raising Special Kids participated in the Arizona Autism Spectrum Disorder (ASD) Advisory Committee and subcommittees representing a broad range of stakeholders to provide recommendations to the Office of the Arizona Governor Policy Advisor for Health and Human Services to strengthen services for treatment of ASD and particularly to respond to the needs of Medicaid members with or at risk for ASD.

ARKANSAS: Arkansas Disability Coalition (ADC) receives funding through a collaborative relationship with AR Children's Hospital (ACH)/Research Institute/University of AR for Medical Sciences to partner on a HRSA Autism Implementation Grant. Through this project, ADC trains and helps health care professionals to better understand the needs and challenges of families of children/youth with special health care needs.

CALIFORNIA: Family Voices of California hosted its 15th annual statewide Health Summit in February 2017. The Summit brings together families, advocates, state agency representatives, health policy advocates, legislative representatives, providers and insurers. Participants learn about pressing and emerging statewide health care policy issues affecting CYSHCN, how their families will be impacted, and how to be effectively involved.

COLORADO: Family Voices of Colorado partners with El Grupo VIDA, a network of Hispanic/Latino parents that provides mutual support for families and empowers people with disabilities and their families with information and training to help them be their own best advocate. This year, the two organizations hosted a parent and professional conference for Hispanic Latino Spanish Speakers with more than 150 participants.

CONNECTICUT: PATH youth project, CT KASA (Kids as Self Advocates) is in its 4th year, with a membership of 25 young adults. They hosted a summit in May 2017 for 90 youth with disabilities. A special highlight was a healthcare social media town hall discussion about mental health, isolation in school, and navigating the healthcare system as a young adult with disabilities.

DELAWARE: Delaware Family Voices' monthly Managed Care Organization Call regularly averages 35 providers and family leaders. This highly respected opportunity identifies complex problems faced by families and educates families and providers on Medicaid procedure and policy. This year two calls are being held completely in Spanish. State Medicaid is very impressed with the turnout and the outcomes of the calls, and are correcting some issues parents brought up that are unique to non-English speaking families.

DISTRICT OF COLUMBIA: Advocates for Justice's mental health initiative brings families, professionals, and community members together to discuss and educate on available resources, how to access them, and policy changes that are needed to take place to improve mental health outcomes for DC's Children. The F2F developed a tool kit on "*Kids Mental Health Services in DC: A Handbook for Parents and Guardians.*"

DISTRICT OF COLUMBIA: Family Voices of DC is currently funded by the District of Columbia Health Benefit Exchange Authority (HBX) to serve as In Person Assisters/Navigators under the Affordable Care Act. Trained CHSCN parents who speak Amharic, Spanish, and Vietnamese helped low and moderate income uninsured families connect to Medicaid and/or the health exchange marketplace.

FLORIDA: Family Network on Disabilities/Family STAR collaborates with other state and national organizations to reach families. On a local level, they work with support groups and promote sustainability and self-advocacy for family members. Through support groups, Family STAR helps parents and guardians develop their own voice.

GEORGIA: P2P of Georgia houses regional coordinators in specialty clinics that serve underserved populations in an effort to be more family centered and also to increase access to the medical home. When a family comes in for their medical appointment, after they see the doctor, they get to meet the Regional Coordinator, who then is able to connect the family to local resources, match them to another family for emotional support, and provide information that includes transition to adulthood.

HAWAII: Hilopa'a assisted many families of children with children with complex needs to obtain coverage with the DD/ID Medicaid Waiver to access respite and personal assistance/habilitation services. These services eliminate out of pocket costs for non-covered respite and in home paraprofessional support. When one family had attempted twice on their own to obtain waiver services but been unsuccessful, the F2F intervened for a third application and helped the family obtain a successful outcome.



IDAHO: Idaho Parents Unlimited collaborated with the Department of Health and Welfare - including the Division of Family and Community Services, Title V, Foster Care, Child Protection Services, and Medicaid, along with the Consortium of Idahoans with Disabilities to improve children's access to mental health services in a manner that includes the family at every level of decision-making and improves the health outcomes for these children.

ILLINOIS: Arc of Illinois held its 10th Annual Healthcare Conference this year. They work with the state Medicaid agency staff liaisons for timely resolution of case advocacy situations, and have revised key fact sheets for families in both English and Spanish.

INDIANA: Family Voices Indiana hosted its first Heart to Heart Conference that included sessions about funding access, special education, next steps after ASD diagnosis, transition to adult care, and more. Some sessions were offered in Spanish. More than 100 families and professionals attended the conference.

IOWA: ASK Resource Center provides information, resources, trainings, family to family mentoring, advocacy, growing and coaching leaders - reaching more than 50,000 individuals with disabilities, their families, and professional partners through one-on-one contacts, trainings, visits to their website, and partnering with other organizations, agencies, and community-based initiatives—at a cost of only \$2.82 per person served.

KANSAS: Families Together/F2F HIC was recognized by Family Voices National for its “Promising Practices in Cultural Competence.” Our continued outreach and acknowledgement of cultural differences has allowed us to support diverse families who have children with special needs in a setting that is trusting and reflective of diversity.

KENTUCKY: Kentucky F2FHIC has dedicated support parents to work with the Hispanic community in response to a tremendous need for services. The support parents work within a pediatric practice, which makes it easier for the family to access their help. As the support parents work with families they build the relationship and trust encouraging the families to take on more responsibility as they learn how the system works. Supported families grow in confidence and become more independent in accessing systems. Through mentorship families become leaders who help other families.

LOUISIANA: Bayou Land Families Helping Families was instrumental in successfully educating public and policy makers about the impact of Developmental Disability services and Early Intervention programs threatened with budget cuts. Thanks to tireless advocacy efforts, all services were restored. The F2F is the only agency in Louisiana that offers families and professionals training on services on accessing available services for CYSHCN including accessing their managed care services.

MAINE: Maine Parent Federation (F2F) and New Directions for Maine Families (SAO), with partners, is preparing to offer the “Leading by Convening” training to staff, peer-to-peer leaders, and Maine families, following up on the training held last fall at the Office of Special Education Programs Regional Conference.





MARYLAND: Parents' Place of Maryland, in collaboration with the state Title V – CYSHCN, conducted eight regional Family Focus Groups across the state engaging families and caregivers of CYSHCN in their communities. Participants created individual Care Maps for their children and used them as a tool to engage their thinking regarding services they currently receive, where any gaps in services occur, and what barriers contribute to those gaps. As a result of these focus groups, a state Care Coordination report was produced and shared with participants and stakeholders.

MASSACHUSETTS: Massachusetts Family Voices @ the Federation for Children with Special Needs is working on a cultural broker model with the Haitian Creole community to provide workshops on accessing healthcare and to train their community leaders to share the workshops within their communities.

MICHIGAN: Michigan Public Health Institute activities include development of a statewide Family Leadership Network in partnership with the Title V CSHCS Family Center; dissemination of information and resources to 406 families at various conferences across the state; participation of 80 families in Empowering Families training in which they received resources related to care coordination; and provided support for 13 families to serve in a leadership role on the MI F2F Advisory Board including 41% from under-represented and/or minority communities.

MICHIGAN: Arc Michigan/Family Voices of Michigan presented two collaborative learning opportunities for families of CYSHCN, including extended family and other support people. The first was an onsite workshop, *How to Better Understand Medicaid and Your Mental Health Rights*, addressing rights, responsibilities, and complaint policies for individuals receiving Community Mental Health, Hospital Mental Health, and Medicaid services. A second event, *Navigating the Social Security and SSI System*, helped participants understand benefits and how to access the systems.

MINNESOTA: Family Voices of Minnesota has an active state-wide presence with Parent Support Navigators located regionally around the state and in the Twin Cities metro area. We also have 135 Volunteer Support Parents including representatives from diverse communities. Family Voices of MN partners with PACER Center to implement the F2F Health Information Center, which has successfully carried out an eight month annual Family Leadership Institute, preparing families to enhance their advocacy roles, serve as advisors and impact public policy.

MINNESOTA: PACER has created a Pediatric Resident Training Program (P RTP) Toolkit to help increase the number of medical professionals prepared to care for youth and young adults with special health care needs or disabilities in their communities. The toolkit contains detailed information on how to provide training to health care professionals working with youth and young adults who are transitioning from pediatric health care to adult providers.

MISSISSIPPI: Institute for Disability Studies at the University of Southern Mississippi has established and developed a partnership between the MS F2F and Hinds County Head Start to help parents and their children transition into kindergarten. Parents are given training at the center locations to assist them in becoming better advocates for their CYSHCN in subjects such as parent involvement and participation, medical home, procedural safeguards, effective communication and also on the 6 key measures of quality health care.



MISSOURI: Missouri Family-to-Family Resource Center was instrumental in building the capacity of support coordinators to provide family centered services within the Title V: Special Health Care Needs and DMH: Division of Developmental Disabilities Programs. These systems adapted policies to support families through provision of family centered information, resources, and networking opportunities with other families.

MONTANA: PLUK families led a series of legislative forums resulting in Medicaid Expansion, Autism services included in Medicaid state plan, and the ABLE Act passage. Because of PLUK families and staff involvement in Systems of Care, PLUK established a Care Management Entity that provides Care Coordination using High Fidelity Wraparound services billable to Medicaid and other entities. This serves as a model for providing peer support services across systems.

NEBRASKA: PTI Nebraska participated in state Health and Human Services meetings to facilitate accessibility and function of the Developmental Disability Services application. This work, as part of a large statewide group, reduced the application for services from 24 to 3 pages and the entire eligibility process is now taking 14 - 21 days instead of more than 90 days. This F2F work facilitated service acquisition, and improved state efficiency and cost spending.

NEVADA: Nevada Family Ties collaborates with the Mexican Consulate's R.E.A.C.H. (Research, Education, and Access to Community Health) program to offer direct support and resources to the families and individuals who visit the Consulate and during the Consulate's special events. Family TIES was recognized at the 2015 REACH/Ventanilla de Salud 2nd annual R.E.A.C.H. "Promotores" and Providers Recognition ceremony in partnership with the Consulate of Mexico. This Award recognizes community partners that assist R.E.A.C.H. in making a difference for all communities, but in particular, the Hispanic/Latino community.

NEW HAMPSHIRE: New Hampshire Family Voices uses Facebook to assist in family connections and parent to parent support, as well as sharing information and resources to families and professionals working with CYSHCN. They are currently partnering with the NH Chapter of the Academy of Pediatrics on a project to increase connections between the chapter and family organizations. Their Medical Home project is working to establish a baseline data system of practices with established transition policies.

NEW JERSEY: SPAN partnered with NJ's Help Me Grow, Early Childhood Comprehensive Systems project, the Infant-Child Health Committee, and the Community of Care Consortium for CYSHCN Screening Committee, co-chaired by SPAN's Learn the Signs. Act Early Ambassador, to develop and disseminate a NJ-specific Well Child Visit Developmental Passport (in English and Spanish), for use by parents during well child visits, with space for information on physical development, immunizations, head circumference, and results of developmental screens.

NEW MEXICO: Parents Reaching Out has created the first family focused healthcare financing ECHO clinic. The technology and technical support from Project ECHO enables PRO to educate and link families and providers throughout the state and the country regarding healthcare costs and other related issues for children with special healthcare needs, as well as gaps in care. The ECHO clinic has helped connect families to resources for healthcare related goods or services when they were otherwise going to have to use a "gofundme" website or other fundraising efforts to pay bills.

NEW YORK: Parent to Parent of NYS maintains a listserv for Medically Fragile Families and use this listserv to reach out to families in times of emergencies and disasters. After Hurricane Sandy left massive damage, including extended loss of power in the downstate regions, they were able to check in with families they knew to have children requiring ventilator use at home, and see that they received the help they needed.

NORTH CAROLINA: Exceptional Children's Assistance Center's focus has been on under-served groups: teens in transition, immigrant Spanish-speaking families, families at or near poverty, and families without insurance. They are shifting from an on-site workshop model to delivering content electronically and via social media. An effort to work with tertiary medical center in order to realize a broader impact is also ongoing.

NORTH DAKOTA: Family Voices of North Dakota increased family voices at the legislature, boards and committees across the state including via our Parent Leadership Institute which prepares 25 parent leaders each year; they are holding the 10th Institute this June. They are grateful for the support of their many partners from across the state.

OHIO: Cincinnati Children's Hospital Medical Center provides education and advocacy on needs of CYSHCN and their family members to managed care organizations and recommended to managed care organizations that they include family members of CYSHCN on their Advisory Groups. They have expanded their successful transition booster sessions across the state for family members and professionals on planning for life after high school.

OKLAHOMA: Oklahoma Family Network is celebrating 20 years of family to family sharing of support, guidance, and encouragement through a variety of services and resources, serving thousands of families throughout the state. Through their SoonerCare Member Advisory Task Force, they made the member handbook "family-friendly," streamlined TEFRA policies, organized regional focus groups, and identified after-hours providers for members.

OREGON: Oregon F2FHIC was given a two-year sub award from the Oregon Health Authority to curate and disseminate condition-specific resources for families of children who experience birth anomalies. The administrators of the Birth Anomalies Surveillance System wanted to partner to ensure that information about the 50 most common birth anomalies in Oregon is available to all Oregon families. Taking a strengths-based approach, the resource guides feature up-to-date information about family support organizations, family stories, and other resources.

PENNSYLVANIA: PEAL Center's 11th Annual Inclusive Communities Conference attracted over 650 parents, youth, and professionals to take advantage of sessions on policy, health care, education, transition, friendship, employment, technology, networks, managing stress, financial planning, and more.

RHODE ISLAND: RIPIN Family Voices 11th Annual Partnership Conference: Supporting the Caregiver was held in April. The event was attended by family, friends, and professionals who provide care for individuals across the lifespan. Speakers provided practical ways for caregivers to monitor their own wellness, cope with the stress of caregiving, and avoid burnout and fatigue.

SOUTH CAROLINA: Family Connections of South Carolina's "Latinos Making Connections" initiative is aimed at better serving the needs of the Latino community. They increase the knowledge and confidence of Latino families in accessing community-based services for children with intellectual and developmental disabilities. The program is based on a philosophy that individuals with shared experiences provide a sense of acceptance, understanding, and credibility.



SOUTH DAKOTA: South Dakota Parent Connection, with support from the state EHDl program, has implemented a Deaf Mentor Pilot Program for families of infants with identified hearing loss. Deaf Mentors support family/child relationships, language development, and development of a child's unique potential through language models/activities in the family's chosen methods of communication and personal perspective related to hearing loss.

TENNESSEE: Tennessee Disability Coalition collaborated with LEND trainees and the TN Department of Health to create the TN DOH Youth Advisory Council, consisting of 12 youths who have SHCN/ disabilities/chronic illnesses. This Council will work with the CYSCHN Section (Title V) to improve the quality and coordination of youth efforts and supports critical to improving outcomes for all youth and especially those with special needs. This Council will provide an opportunity for youth to gain leadership skills and learn from state leaders about policies that affect them.

TEXAS: Texas Parent to Parent has been doing a Medical Education Program (MEd.) for the past 15 years to train pediatric and family practice residents and medical students about the global effect of having a child with a disability or special health care need through contacts with Family Faculty. They recently began providing this training through Google Hangout as a telemedicine platform for residents and parents, getting participants used to learning in this way.

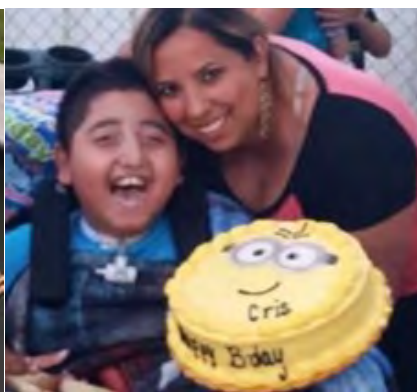
UTAH: Utah Family Voices staff proposed a leadership project to the Utah Regional LEND program (which was accepted) to research and develop a Clinical and Emergency Assessment Tool to be used to help diagnose pain and health problems for children with disabilities and limited communication who are often misunderstood in the clinical setting.

VERMONT: Vermont Family Network has expanded their work extensively with the UVM Children's hospital including the Patient and Family Advisory Committee, Child-Life, and hospital "Creativity Teams" whose focus is to improve services and supports for patients. They have also added a new program, "Puppets in Education," that teaches children how to keep themselves safe and healthy and to appreciate each other's differences.

VIRGINIA: Virginia Center for Community Involvement has established collaborative partnerships with Virginia's state agencies (Medicaid, health, education, vocational rehabilitation, and developmental disability services). These agencies value these partnerships as evidenced by state contracts (\$1.1 million) and representation on over 12 state level committees providing a minimum of 400 hours of technical assistance annually on family engagement, youth leadership, employment of people with disabilities, care coordination, and long term care services.

WASHINGTON: PAVE partnered with FV National and Idaho F2F in a Patient Centered Outcome Research Institute initiative around diabetes, at risk communities, and community and family engagement focused on making healthy food choices. They reached out to Muckleshoot Tribe families and later added a community health organization. Participants identified the priorities of access to traditional foods and healthy cooking techniques.

WEST VIRGINIA: West Virginia F2FHIC has improved the quality of service delivery related to Care Coordination and the Medical Home for families and CSHCN through a redesign of the WV CSHCN policy and procedures for CSHCN. They assist with a level of needs assessment and improve the medical home by attending home visits, participating in clinics, and assisting with the assessment and care plan development for CSHCN. The program expanded direct services to CSHCN and their families pertaining to youth transition from Pediatric to Adult Health Care through attendance at DHHR transition clinics in West Virginia.





WISCONSIN: Family Voices of Wisconsin, as a member of the Survival Coalition (a cross-disability statewide coalition), successfully advocated for increased funding to eliminate waiting lists for children with long-term support needs. Family members met with staff in the Governor’s office, sent family stories, and made visits with their elected officials to promote this and other important proposals in the 2017-2019 state budget. When the Governor signed the state budget into law in late September, an increase of \$19 million was included in the budget!

WYOMING: UPLIFT provides one-on-one support across the state via the F2F Health Liaison. They serve families of children with complex behavioral health needs with High Fidelity Wraparound care, and provide educational advocacy services for families statewide. They are contracting to provide qualified respite care on FE Warren Air Force Base for families of children with moderate or severe health needs.

WYOMING: Wyoming Institute for Disabilities offers Friendships & Dating, a preventative training program that teaches individuals with intellectual and developmental disabilities how to develop and maintain healthy relationships. They also offer the Wyoming Family Mentorship program, pairing newly diagnosed families with families who have been navigating systems for some time, to ensure that families that have a child with autism spectrum disorder have the support, resources, and community they need to thrive.

