



Friday's Child

Congratulations to the 51 F2F HICs receiving funding from HHS!

READ MORE AT <http://www.familyvoices.org/news/latest?id=0111>



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Federally Qualified Health Centers and F2F HICs in Partnership: A Gold Mine of Opportunity

Building on a 2011 F2F HICs Grantees Meeting presentation, Matthew Burke, M.D. Senior Clinical Advisor, HRSA | BPHC | Office of Quality and Data, Mercedes Rosa (NJ F2F Statewide Parent Advocacy Network/SPAN), and Christy Blakely (CO F2F/Family Voices Colorado) shared additional tips for establishing and cementing partnerships between Federally Qualified Health Centers (FQHCs) and Family-to-Family Health Information Centers (F2F HICs) in a recent teleconference.

The F2Fs and FQHCs can benefit each other through shared resources and access to patient populations, Matt indicated. Typically the FQHCs see a larger percentage of the population in a given area than do the F2Fs, but may not have the specific CSHCN resources that the F2Fs can provide, or may not know where to find them.

SPAN and an FQHC, through a CHIPRA Immigrant Outreach grant, piloted a program that included 24 parent trainings, in English and Spanish, around the Medical Home initiative with a focus on chronic conditions such as sickle cell and diabetes. They shared Early Intervention resources and tools—ensuring families could get connected to the program for needed support.

The Colorado F2F also worked with CHIPRA funds. Through Medical Home certification, they provided the FQHC information about needed improvements including more effective communication. They identified 4 to



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resources for disease-specific diagnoses that could be made available to families as they left the hospital.

“Resources have to be ‘family-friendly’ to be effective,” Mercedes explained. “We asked families what they knew about the Medical Home and they responded, ‘What a novel idea! Where is this place?’” Acknowledging that F2Fs are stretched, financially and time-wise, she emphasized that “we can find big and small ways to support the FQHCs” that fit into the MCHB core outcomes.

Initial Colorado quality improvement surveys indicated that Spanish-speaking families needed information on education, health, transition, and more. Partnering with other community organizations, the F2F created a community-based session as part of a Spanish-only all-day training. “It was low budget, but we got it done. We got families the information they needed, and by partnering, we showed the community and the FQHCs

News From Our Partners



National Health Care Transition Center

Got Transition Website Launched

Check out the new Got Transition website, still under construction with more content to come:

www.gottransition.org.

National Center for Project Access (NCPA)

New Website

Project Access seeks to increase awareness of epilepsy and improve access to coordinated, comprehensive care for children and youth with epilepsy in medically underserved and rural areas. The NCPA provides national leadership, technical assistance and support to state grantees, and serves as a clearinghouse for epilepsy-related resources.

www.accessforepilepsy.org

AMCHP

AMCHP-FAMILY VOICES 2011 Conference Archives Available

Did you miss a session at the AMCHP/FV conference in Washington, DC, last February? Check the archives now available at:

<http://webcast.hrsa.gov/conferences/mchb/amchp2011/>

CityMatCH

Emerging Leaders Scholarship Fund

CityMatCH is awarding a \$1000 stipend for conference-related expenses at the 2011 CityMatCH conference later this year for individuals who have not previously attended a CityMatCH conference, work in a CityMatCH Member Health Department, and have at least 5 years of leadership or supervisory experience. Applications are due Wednesday, June 15, 2011:

www.citymatch.org/Conference/2011ScholarshipInstructionsandApplication.doc

the resources that community-based organizations have and are willing to share."

Matt emphasized, "There is only so much that can be done from the top down. Communities are so unique and the F2Fs know them better than we can. We just want to make sure there is mutual understanding and that we build on pre-existing relationships—it's important to have these conversations."

Diana Denboba, Branch Chief, Maternal Child Health Bureau, reminded F2Fs to share the rich data available through the National Survey of Children with Special Health Care Needs on state-specific demographics and other issues important at the community level. States with existing coalitions and those looking to start one can bring in the FQHC. The partnerships that result can only help the families and the professionals dedicated to serving them.

To find a FQHC go to <http://bphc.hrsa.gov/>.



Legislative Corner:

Washington Update

The buzz in Washington these days has to do with the federal budget and, most important to CYSHCN, whether the scope and nature of the Medicaid program will remain an "entitlement" as it is now. Some Members of Congress are insisting on significant cuts in federal spending in exchange for voting to increase the nation's debt limit, which is considered "must-pass" legislation to prevent a default on the nation's debt. Therefore, negotiations are taking place among the House, Senate, and administration about ways to reduce federal spending, and Medicaid is one of the places they are likely to look for savings.

Under one proposal, which was approved by the House, Medicaid would be turned into a block grant, meaning the federal government would provide fixed Medicaid payments to states, instead of matching state expenditures as they do now. In addition, states would be given great flexibility in running their Medicaid programs because federal mandates would be lifted. The fixed federal payments (block grants) would not keep pace with health care costs, leaving the burden on states and localities. In such a situation, it is almost certain that states would cut back on Medicaid eligibility, services, and/or reimbursement to providers.

It is not expected that this block grant proposal will advance in the Senate. Nevertheless, Medicaid is vulnerable, since it is a significant expenditure for both the federal government and the states, and since its constituency is historically less powerful than those fighting against cuts in Medicare and Social Security. Even the President has proposed a (much smaller) cut in Medicaid, although not through block granting or any changes in requirements related to eligibility or services.

The Family Voices policy team and other child health advocacy groups are making a concerted effort to educate Members of Congress on the negative consequences of severe cuts and/or block grants in the Medicaid program.

Contact Brooke Lehmann (Blehmman@familyvoices.org) or Janis Guerney (Jguerney@familyvoices.org) if you have any questions.

News You Can Use



- KASA Webinar Archive Available**
If you missed the April 27th webinar—"The 411 on National Kids as Self Advocates (KASA)" with KASA Task Force and Board members—the link to the playback is now available. The young people did a super job sharing information, resources, and their stories, and responding to questions from the field. Click on: www.323.livemeeting.com/cc/familyvoices/view?cn=&id=67R6P7 to view the recorded webinar. Enter your name. A Recording Key is not required. Then click the View Recording button.
- Oral Health Resource for Patients with Special Needs:** The University of Washington School of Dentistry has created this resource for patients with special needs. Information is provided for several disease-specific conditions, from ADD/ADHD to cerebral palsy and HIV. http://dental.washington.edu/departments/omed/decod/special_needs_facts.php
- Health Literacy Assessment Instruments:** We know health literacy—ensuring that patients and families fully understand the medical and health information they are given—is important. Here's a website that lists commonly used health literacy assessment instruments, both for research and clinical settings. <http://nchealthliteracy.org/instruments.html>
- Videocaregiving:** This website, www.videocaregiving.org, and its Spanish companion, www.videoasistencia.org, are all-video websites to help the estimated 50 million family caregivers in the U.S. better understand and cope with their situation.
- Keeping Medical Records:** What medical records are important to keep—and why? You'll find some great tips here. <http://kidshealth.org/parent/>

Friday's Child is a monthly e-newsletter providing news and resources from the Family Voices network and the broader community of families and friends of children and youth with special health care needs/disabilities. Subscribe at: <http://www.familyvoices.org/projects/NCFPP>



Family Leadership in the States:

Community-Based Partnerships in New York State Expand Reach to Underserved Families

Community-based support for children with special health care needs does not spring up overnight. It is often built on existing connections between people passionate about their advocacy work. Such is the case for the unique partnership between **New York State's F2F HIC/Parent to Parent (P2P)** organization and Bronx Lebanon Hospital Center's (BLHC) Autism Parent Support Group.

The BLHC support group, created in 2002 by Dr. Ram Kairam, Chair of Pediatrics and Director of the Autism Treatment and Advocacy Center, started small but has grown to 35-40 active parents and/or caregivers. The support group is representative of the economically underserved and culturally diverse South Bronx population.

Many individuals with autism exhibit other disabilities such as hyperactivity, mental retardation and epilepsy.

The BLHC support group focuses on supporting a minority population and also provides an excellent opportunity for these and other parents to learn from the larger P2P/F2F HIC world of parent resources and support. Millie Suarez-Milligan, Parent to Parent Regional Coordinator and a recognized "community connector," combined forces with Dr. Kairam and the two realized the potential for expanding outreach efforts.

Alexandra Meis, Clinic Coordinator at Bronx Lebanon, noted that the BLHC support groups—held in English, with translation available for Spanish and French—provide a safe place to talk. "A support group isn't a place where you have to talk, but where you can talk when you are ready to talk." It is satisfying to see these parents giving encouragement to others. Parents exchange phone numbers, offer to babysit, and meet in the park. These new connections provide opportunities for everyday living that seemed impossible to many.

Millie indicates some of the struggles for parents from other cultures caring for a child with a developmental disability like autism. "Language is an issue, as well as cultural differences. A lot of these parents who live in the Bronx—even if they are here legally—are from environments where they are used to being given what they are given, and that's it. They don't know that they have the right to speak up for their children."

A trusted leader/resource often emerges in a group setting. "I've noticed there's always a parent leader within the group to whom other parents gravitate, because she may understand English, work in a school, or isn't afraid to seek out information," observed Millie. This led to the idea of "support circles," in which these natural leaders would go back into their communities to provide resources, accurate information, and encouragement to other parents to seek help through both BLHC's Support Group and the P2P network.



more
**Family Leadership
 in the States**

**Family-to-Family Leaders in
 North Dakota Shine!**

Family Voices congratulates four ND parent leaders who were honored for their work on behalf of children and families.

In April, **Brenda Schmid** was honored as Advocate of the Year by the Metro Area Mayor's Committee, in Fargo, North Dakota, for her work in supporting families of children with special needs by reducing barriers for inclusion. Brenda is the F2F Family Consultant in Fargo.



The Burckhard Family

Paula and Kevin Burckhard were awarded the Glenda Schepp Dedication Award at the Pathfinder Parent Center Conference (ND's PTI). This award is given to parent leaders who exemplify the Pathfinder spirit, integrity, and exceptional dedication for building better educational futures for North Dakota children with disabilities. Paula has served as F2F Family consultant in the Minot area since October 2010.

The Centers for Disease Control and Prevention (CDC) has recognized **Roxane Romanik** as a Champion for Families, commending her efforts to help families of children with autism connect with services as early as possible after receiving the diagnosis. Roxane has volunteered countless hours for the ND F2F HIC. Learn more about Roxane and CDC's "Learn the Signs. Act Early" campaign at www.cdc.gov/Features/AutismChampion

Visit the F2F in ND, Family Voices of ND, at <http://www.fvnd.org/>.

CONGRATULATIONS, ALL!

Alexandra and Millie agree that this collaboration was deliberately slow in development. They took time to observe the community, listen to them, and attend meetings before they started writing plans and talking about how both the BLHC support groups and P2P NY programs could best serve the community. "We wanted to break into the community but wanted to make sure we did it in the right way," Millie concluded. Their careful planning and coordination has reaped far-reaching benefits.



NEWS from Family Voices:

Family Voices has undergone tremendous growth and change over the last few years. At the direction of our Board of Directors, and with guidance from staff, family and youth leaders, Family Voices developed a 4-year Strategic Plan (2008-2011) focused on four areas—Infrastructure; Policy; Cultural Competence; and Funding. This summer the Family Voices Board will meet to develop a Strategic Plan for 2012-2015. We look forward to continuing to work with you—family leaders, partners and key stakeholders—to ensure that families are kept at the center of children's health care. Now, more than ever, our voices must be heard as the system debates proposed changes that will affect all of our nation's children and families.

As we reflect on our past and plan for our future, we pause to recognize three Family Voices staff members who are leaving Family Voices this summer. **Betsy Anderson**, Director, IMPACT project, is no stranger to those within the family leader movement and to our federal partners, having been with Family Voices since the beginning and a dedicated advocate in the Maternal Child Health world for most of her career. Betsy has tirelessly worked to ensure that all families understand available services and are supported in becoming leaders who participate in meaningful ways in the design and evaluation of programs like those supported through Title V Block Grants. At the recent Federation for Children with Special Needs 2011 Gala, Betsy was honored with the President's Award for her role as co-founder of the Federation and her substantial contributions to the world of health care advocacy for CYSHCN. Read more at <http://fcsn.org/gala/2011/anderson.php>. Betsy is retiring to spend more time with her children and grandchildren.

Rachel Rodriguez, Deputy Director, has during her tenure done much to better define and streamline administrative roles and functions and focus our organizational development, technology, publications, FV branding and fundraising efforts. Rachel has been instrumental in creating our new website; managing our new membership structure and creating annual reports. She leaves Family Voices to spend more time with her family, including her precious new baby, Mateo.

You will not find a more committed group of leaders than the Kids As Self Advocates (KASA) Task Force and Board members who, under the leadership of **Naomi Ortiz**, Director, have developed numerous outstanding resources on self-advocacy, disability history and pride, and youth leadership. Naomi has guided and supported family leaders in better understanding their role as adult allies to young men and women with disabilities, and how to support youth leadership in their states. Naomi leaves Family Voices knowing she has given her all to this project and is now ready to explore new endeavors.

These three women have contributed to our continued success in so many ways and will be missed by all. Thank you, Betsy, Rachel, and Naomi!

