Family/Professional Partnerships: Moving the Needle

-by Nora Wells, FV Executive Director

In 1972 when my young baby needed medical care, family-centered care was an idea waiting to be born. And so, I waited—to hear when I could visit him, to connect with someone like us, to find out if an insurance plan would accept him.

By the middle of that decade, things began to change. Families across disability groups worked with educators to pass special education laws giving families new roles in decision making. Health care was also changing. In the 1980s, visionary leaders at MCHB began to work with families in new partnerships—defining family-centered care, medical home, community based systems of care, and 6 core outcomes with expectations for family professional partnerships.

Family Voices came together in the early 1990s, to infuse family perspectives into programs and policy. In 2005, legislation created Family-to-Family Health Information Centers (F2F HICs), MCH-administered grants to each state, through which millions of individual families have been assisted in partnering and young and diverse families have been nurtured to take leadership roles throughout the country.

Over these years, science has made many advances in health care. Change has also come in our thinking about the roles patients and families play in our health care systems. In concept, though not always in reality, partnerships are expected, at individual and even policy levels.

We have learned that engaging the “family voice” is the most fundamental way to ensure that family needs will be met and that programs meant to serve families will be valid and effective. But, there is still much work to do. Many families of children/youth with special health care needs and others experience little family-centered care, especially those from diverse socio-economic, racial and linguistic backgrounds, as well as families of children with complex needs. These families, particularly, need their voices heard to overcome health disparities. Funds invested in F2F HICs have demonstrated that families of all backgrounds have knowledge and skills needed to improve health care. Training, mentoring and support from peers help families from underserved communities, as well as all families, become better partners with their child’s providers and strengthen their community voice in program and policy decisions.

F2F HICs have developed models for effective family/professional partnerships. A secure source of ongoing funding for F2F HICs is critical to continue this progress. As the new Executive Director of Family Voices, I look forward to reaching out to partners across our country to help us realize this goal. Sustained funding for F2Fs will help to “move the needle” on improving outcomes and ensuring quality health care for all.

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Public Policy Update:
by FV Policy Team: Brooke Lehmann and Janis Guerney

What does 2015 hold in store when it comes to public policy affecting children and youth with special health care needs (CYSHCN)?

CHIP. Federal funding for the Children’s Health Insurance Program (CHIP) will run out September 30, 2015. Child health advocates and many Governors of both parties are working to persuade Congress to provide continued funding. Without CHIP coverage, many more children will have to get insurance through the Affordable Care Act (ACA) Exchanges (with less child-focused benefits) or will not be able to afford insurance. Nearly 10 million children currently receive CHIP benefits and it is estimated that up to two million will be uninsured if CHIP funding expires.

The F2F program. Federal funding for Family-to-Family Health Information Centers (F2Fs) will run out on March 31, 2015 (although the grants to F2Fs will continue through November, because of the project year). Family Voices is working to secure legislation to extend funding for as long as possible. It is hoped that such legislation will be included as part of a Medicare physician-payment bill expected to be enacted by March 31.

Home Visiting. Funding for the Maternal, Infant, and Early Childhood Home Visiting Program also expires on March 31. A coalition of children’s groups, including the Association of Maternal and Child Health Programs, is working to get this funding extended. The Medicare physician-payment bill might serve as a legislative vehicle to extend funding for this program.

King v. Burwell. In March, the Supreme Court will be hearing arguments in this case. The issue is whether the law permits the provision of subsidies to individuals purchasing insurance on the federal Exchange, rather than a state-established Exchange. The Kaiser Family Foundation estimates that about 13 million people could be denied subsidies in 2016 if the Court rules in favor of the plaintiffs. Without subsidies, many people will not be able to afford health insurance, and the premiums for others would be likely to rise. The Court is expected to issue its decision by the end of June.

The ABLE Act, recently passed, enables families to establish tax-protected savings accounts for their children with special health care needs for the first time this year, without jeopardizing their eligibility for Medicaid or Supplemental Security Income (SSI). These accounts, similar to “529” college savings plans, can be used for a variety of purposes, including education, housing, transportation, employment training and support, assistive technology and personal support services. Those eligible for an ABLE account are children who meet the SSI program’s disability standard for children, and adults whose disability occurred before the age of 26 and who meet the SSI disability standard for adults.
News You Can Use

Fact Sheet: Reviewing and Amending Medical Records
This fact sheet from SPAN of NJ summarizes important information for families regarding their right and need to review medical records for procedures including hospitalization. http://www.spanadvocacy.org/content/reviewing-and-amending-medical-records-fact-sheet

Webinar Series: Transition of People with Special Healthcare Needs to Adult Medical Care
The New York - MidAtlantic Consortium for Genetic and Newborn Screening Services is hosting a series of seven webinars from 2/11/2015 through 5/6/2015 for both providers and families. Youth and families are encouraged to attend to better understand their role in medical care transition. http://www.fv-ncfpp.org/news/transition-components-information-and-successful-system-models/

Pediatric Starter Kit: Having the Conversation with Your Seriously Ill Child
This resource from the AAP Council on Children with Disabilities offers advice and provides stories from parents and palliative care specialists about end-of-life care conversations. http://theconversationproject.org/starter-kit/intro/

Families & Medicaid Stories Needed

Family Leadership in the States:
Family Voices of Colorado:
Helping Families: Strategies for Success
by Tom Rose, Family Voices of Colorado Executive Director

In the past year, more than 10,000 Colorado families requested assistance from Family Voices of Colorado (FVCO), the statewide F2F and FV State Affiliate Organization, representing families from all parts of the state, both metro and rural, including many from diverse populations suffering health disparities.

FVCO is often the first organization to notice harmful trends and system failures that cause hardships and health inequities for families, and may be the last organization that can help. Our advocacy begins with identifying the needs of families and touches many healthcare systems and providers. Families are our main clients, and our role is to advocate for them and help them become empowered to overcome the health inequities and barriers they face.

FVCO Hospital Family Navigators (two bilingual) assist families of cultural, racial, linguistic, and geographic diversity on a daily basis. Cultural brokers provide culturally competent materials and communicate information in a way that addresses the needs of diverse populations. Health Coverage Guide services have made us known as the barrier busters for any kind of private or public benefits problems that families experience.

From the moment we meet a family we are there to coach and support. The support continues until the family issues are resolved and procedures, rules, regulations, or laws are changed. Our person-to-policy strategy operates at the micro level helping families on benefit appeals or wheelchair ramp approvals, and the macro level working on hospital policies or financing initiatives. This has proven effective for scores of families over the years. We don’t give up until the family experiences a resolution to their problem. Our successes reinforce the critical value of family and person centered support as the underlying core principle in all of our work.

In addition to helping individual families resolve their health care service issues, we actively seek opportunities to share our knowledge of family experiences with policy makers. We currently represent families on over 26 Regional, State, and County committees. F2F Family Navigators provide the “family voice” at an additional 25 State of Colorado commissions, consortiums, and coalitions. In 2012 a Family Voices of Colorado staff member was appointed by the Governor to serve on the Community Living Advisory Group to make recommendations on changing and redesigning Medicaid Waivers to be more effective for families.
Family Voices Project Updates

- Shared Decision Making (SDM)
  Through a contract with Quality Trust for Individuals with Disabilities, Family Voices and Parent to Parent USA will collaborate with aging and disability communities, networks, researchers, professionals, and providers. This project will examine and reform guardianship and SDM law, policy, processes, and methods as needed to make SDM a universally accepted alternative to guardianship and increase self-determination.

- Community Outreach Collaboratives
  The American Association on Health and Disability (AAHD) recently funded 11 Community Outreach Collaboratives (COCs) through their National Disability Navigator Resource Collaborative (NDNRC). Four FV State Affiliate Organizations received funding: Rhode Island Parent Information Network, Family Voices Indiana, Family Voices Colorado, and PAVE Family to Family Health Information Center (Washington State). A fifth FV State Affiliate, Family Voices of North Dakota, was awarded COC funding with the North Dakota Center for Persons with Disabilities at Minot State University. The COCs will increase collaborations in the community, dissemination and outreach efforts and enrollment of people with disabilities in the ACA. National FV will develop lessons learned to be disseminated widely to family organizations.

- Family-Centered Care Assessment (FCCA)
  In a joint initiative between FV and AAP 30 pediatricians piloted the FCCA tool in their practices. Pediatricians participated in training calls, facilitated by a family leader and a pediatrician on Family Centered Care, Shared Decision Making, and Family Support and Resources. A journal article on the tool development, Psychometric Evaluation of a Consumer-Developed Family-Centered Care Assessment Tool, will be published soon in the MCH Journal.
  Download the toolkit at http://www.familyvoices.org/projects?id=0015

- Fast Fact Fridays
  As part of a collaboration with the Child and Adolescent Health Measurement Initiative, FV tweets data every Friday from the Data Resource Center about CSHCN. Follow Family Voices at http://www.familyvoices.org/twitter

What's New with Family Voices!

Partnering Tip Sheets now in SPANISH!
Partnering with Your Child's Provider provides tips for caregivers on preparing for appointments, meeting with their child's doctor, and follow-up activity. Partnering with Your Child’s Health Plan provides tips to help family members meet with their child’s health plan to discuss plan policies for CYSHCN and how partnering with families can make a difference. Download at http://www.fv-ncfpp.org/tools-and-resources/tools-and-resources-spanish/.

Affordable Care Act (ACA) & CYSHCN: Blog & Tip Sheets
Our monthly blog provides information and resources to help families, family leaders, and other stakeholders assist families in understanding and enrolling in health insurance through ACA marketplaces. Visit http://www.fv-ncfpp.org/blog/ and check out the latest tip sheets:
- Copays, Coinsurance, & Deductibles—Oh My!
- How Can Families and Professionals Help Children with Special Needs Keep Insurance Coverage as they Age Out?
- “Churn” - How Does It Affect Families Of Children With Special Needs?

Focus Group Toolkit
As a result of the Family Voices Project IMPACT work over the last 3 years with Family Voices State Affiliate Organizations (SAOs) and Family-to-Family Health Information Centers (F2Fs), a Focus Group Toolkit has been developed to help family leaders facilitate family focus groups around health and wellness topics. This toolkit includes focus group scripts, best practices, checklists, helpful facilitator phrases, evaluation form, staff exercises, and note-taking and analysis guidelines. Download the toolkit at http://www.familyvoices.org/projects?id=0015

Fact Sheet: What to Know When Assisting a Consumer who has a Child or Youth with Special Health Care Needs (CYSHCN)
Family Voices has created this fact sheet for the National Disability Navigator Resource Collaborative, an initiative funded by the Robert Wood Johnson Foundation to provide cross-disability information and support to Navigators and other enrollment specialists to help people with disabilities receive accurate information when selecting and enrolling in insurance through the Affordable Care Act Marketplaces. http://www.nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/population-specific-fact-sheet-child-with-special-health-care-needs/

Family-to-Family Health Information Center 2013-2014 Data Report
A 4-page report that provides highlights of data reported by F2F HICs in 2013-2014 demonstrating the value and impact in helping families of CSHCN. Family quotes are included as well as highlights of the 2009/10 NS-CSHCN. Available at http://www.fv-ncfpp.org.