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TESTIMONY

on

Examining the Advancing Care for Exceptional Kids Act

before the

Health Subcommittee

House Committee on Energy & Commerce

July 7, 2016

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Summary of Testimony
Examining the Advancing Care for Exceptional Kids Act
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Medicaid provides critical support to children with complex medical conditions and their families, but there are some serious barriers to care. The ACE Kids Act (discussion draft) addresses some of these barriers, including access to out-of-state care and the lack of adequate coordination among multiple health care providers. Family Voices fully supports the goals of the ACE Kids Act and many of its specific provisions, particularly the requirement that the Administrator of the Centers for Medicare and Medicaid Services (CMS) develop best practices to assure access to specialized out-of-state care. Nevertheless, we respectfully recommend several additions and modifications to the bill. Among our recommendations, we suggest that the bill –

- require the Administrator of CMS to develop qualification standards for health homes that are specific to the needs of pediatric enrollees;
- require health homes to coordinate with their state Family-to-Family Health Information Centers;
- require that family leaders associated with family organizations be engaged in the development of the qualification standards for health homes, the health-home State Plan Amendment, and the policies and procedures of individual health homes; and
- require that states adopt the best practices developed by the CMS Administrator regarding access to out-of-state care.

We also urge that the Subcommittee examine the "medical home" model and consider broadening the definition of "child with medically complex conditions."

Good morning Mr. Chairman, Mr. Ranking Member, and Members of the Subcommittee. My name is Maria Isabel Frangenberg and I am a Project Coordinator for Family Voices. Family Voices is a national nonprofit organization of and for families of children and youth with special health care needs (CYSHCN) -- those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.[1] Children and youth with special health care needs may have physical, developmental, or intellectual disabilities (e.g., cerebral palsy or autism), chronic health conditions (e.g., diabetes or epilepsy), serious illnesses (e.g., cancer), rare genetic diseases (e.g., mitochondrial disorders), severe injuries (e.g., traumatic brain injury), mental health conditions, or other conditions requiring frequent health care services.

Family Voices is entering its 24th year as the national, cross-disability, family-led organization dedicated to "*keeping families at the center of children's health care.*" Through our national grassroots network of families and family organizations, we provide families with resources and support to make informed decisions, advocate for improved public and private policies, build partnerships among families and professionals, and serve as a trusted resource on health care.

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[1] This is the definition used by the Health Resources and Services Administration. From: McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*, 102(1):137–140, 1998.

Prior to working for Family Voices, I served as the Latino Community Liaison for the Family-to-Family Health Information Center in Virginia. Family-to-Family Health Information Centers (F2Fs) are state-wide, federally funded centers that provide individual assistance and connection to resources to help parents of children with special health care needs to navigate the health care system and work effectively as partners with their children's health care providers. In that and my current position, I have heard from many families about their challenges in getting timely and appropriate care for their children with complex medical needs on Medicaid.

MEDICAID SERVICES FOR CHILDREN WITH MEDICALLY COMPLEX CONDITIONS

Background

The most recent (2009/10) National Survey of Children with Special Health Care Needs found that there were over 11 million children with special health care needs under age 18 in the United States. A subset of these children have "medically complex conditions," although there is no clear definition of that population. These children may need care from multiple pediatric subspecialists (e.g., pediatric cardiologists or neurologists) to treat different body systems. Some of these children have rare conditions in which only a handful of providers, or even a single provider, in the country have expertise. Some of these children need multiple surgeries and hospitalizations, significant physical, occupational, and/or speech therapy, multiple medications, transplants, prostheses, medical foods, and/or special medical supplies or equipment. Some depend on ventilators or other medical technology to survive and may need 24-hour per day monitoring. Today there are more such children than there were in the past, given new medical techniques and technologies that allow them to survive prematurity or problems at birth, or to live longer with chronic conditions than they might have lived a generation ago.

It is estimated that there are about three million children with medically complex conditions in the US, of which about two-third are enrolled in Medicaid.[2] These two million children – approximately six percent of the total number of children on Medicaid – account for about 40 percent of Medicaid spending for children's coverage.[3] For some children, Medicaid is their only source of insurance; for others Medicaid serves as the secondary payer, supplementing a family's private insurance and covering services that private insurance typically does not cover, such as private duty nursing, transportation or respite care.

The critical role of Medicaid for children with medically complex conditions

For children with medically complex conditions and their families, Medicaid can be a life-saver, both literally and figuratively.

An Indiana mother recounted last year: "My family went from a dual-income family with minimal medical expenses to a single-income family with significant medical expenses when my daughter with disabilities was born. Even with private insurance … we were paying upward of $12,000 per year for her medical, pharmaceutical, and equipment expenses including high-tiered medications, out-of-network costs for several specialists, and of course deductibles and copays--to say nothing of the out-of-pocket travel expenses and other non-covered items (prescribed over-the-counter medicines, therapy beyond annual limits, incontinence supplies, Pediasure,

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[2] Many families whose children have medically complex conditions or special health care needs could benefit greatly from Medicaid coverage, but their children are not eligible due to family income or years-long waiting lists for waiver services. This testimony does not address the problems related to eligibility for Medicaid.

[3] Information from the Children's Hospital Association website at https://www.childrenshospitals.org/Issues-and-Advocacy/Children-With-Medical-Complexity/Issue-Briefs-and-Reports/Optimizing-Health-Care-for-Children-With-Medical-Complexity and https://www.childrenshospitals.org/Issues-and-Advocacy/Children-With-Medical-Complexity/Fact-Sheets/Defining-Children-With-Medical-Complexities.

specialized eyeglass frames and lenses, dental work, and more). Since my daughter began qualifying for Medicaid Disability last year...we have made good headway toward paying off medical debt and even saving for college for our other two children. Beyond the very tangible benefits, I have more peace of mind knowing that we will never again have to go into debt to provide for my daughter's complex medical and therapy needs."

A few years ago, another Indiana mother told us about her daughter, Grace Susan Akers. Grace was born with two rare genetic syndromes, and was in the hospital for four months after her birth. Although the family had private insurance, they quickly approached their policy's lifetime cap. The private insurance stopped paying for home nursing, and did not cover the specialized nutrition Grace needed, so the family's out-of-pocket costs were "staggering." Without the Medicaid assistance the family received, Grace's medical expenses, even with private insurance, would have escalated beyond her parents' actual income. Although Grace passed away in 2015, she was able to live at home with her loving parents during the 17 years of her life.

Carissa Malley, from New Jersey, is an example of a child who needs highly specialized treatment for a rare condition, as well as treatment for many less serious health problems. Born with Down syndrome, Carissa had heart surgery as a baby, needs special bi-focal glasses, hearing aids, a bi-pap machine for sleep apnea, and night nursing to monitor her breathing. In addition, Carissa has a rare, life-threatening condition called Pulmonary Hypertension (PH). She receives care from the Pulmonary Hypertension Center at New York-Presbyterian Morgan Stanley Children's Hospital, where the pediatric cardiologists are at the forefront of treatment for this condition. Medicaid has allowed Carissa to get treatment in NY and participate in drug trials when necessary. If she were covered only by traditional private health insurance, it is unlikely that her team of specialists would all be in one network.

Obstacles to timely and appropriate treatment for children on Medicaid with medically complex conditions

Carissa's story is an example of Medicaid working to help children get the extensive and highly specialized care they need, even across state lines. Unfortunately, there are many families who face multiple barriers in getting timely and appropriate Medicaid services for their children with complex medical needs. As identified recently by family leaders from Family Voices state affiliates around the country, some of the more common problems for medically complex children on Medicaid are:

- a scarcity of subspecialty providers (especially in rural areas), or those who take Medicaid, resulting in the need to travel long distances and/or wait long times for an appointment;
- problems with managed care -- an inadequate network of providers; lack of continuity of care due to changing provider networks; and lack of plan experience in dealing with this population;[4]
- lack of or ineffective care coordination (with effective care coordination, all of a child's providers would be well-informed, the "whole child" would be treated, and families would know about all of the resources available to them);
- failure to cover or slow approval for out-of-state or out-of-network care;

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[4] From the National Academy for State Health Policy: "The first wave of Medicaid managed care in the 1990s saw many states carving out services for children and adults with special needs through fee-for-service arrangements. However, these trends have changed dramatically since that time. Recent CMS data and a 2010 Kaiser Family Foundation survey indicate that 32 states mandatorily enroll at least some children and youth with special health care needs (CYSHCN) in managed care, 20 states enroll CYSHCN in managed care on a voluntary basis, and about half of states mandate managed care for at least some children who receive Supplemental Security Income (SSI)." (Source: http://www.nashp.org/early-highlights-of-what-the-final-managed-care-rule-for-medicaid/)

- long-waiting lists for and incomplete information about Medicaid waivers;
- failure to translate written communications from the Medicaid agency and lack of interpreters during medical appointments for families who are not proficient in English;
- lack of "cultural competence" on the part of health care providers and the Medicaid agency;
- inadequate coverage of medications, medical equipment, medical supplies, hearing aids, medical foods, and other necessities;
- inadequate coverage of nursing services, therapeutic services (e.g., and occupational, physical and speech therapies), and non-medical services (e.g., transportation, respite, home or vehicle modifications, family lodging for out-of-area care);
- failure to integrate mental health and medical services and lack of provider expertise in treating children with co-occurring diagnoses;
- insufficient access to home and community-based care (forcing children into nursing homes rather than allowing them to be cared for at home); and
- inadequate preparation for transition to adult-care services when a child ages out of coverage for Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services.

In addition, family leaders, family members who work for and are trained by family organizations, find that some state Medicaid agencies, managed care organizations, and health care facilities do not meaningfully engage or consider the input of families and family organizations in the development, implementation and evaluation of their organizational policies, procedures, programs, and practices. As a result, they are missing opportunities to address some of the issues mentioned above, and thus improve patient care and family satisfaction. The topic of family engagement is discussed further in our comments about the discussion draft, below.

Following are some accounts from families about the struggles they have had getting Medicaid services for their children with complex medical conditions:

In North Dakota, a widow is raising two children with a rare, extremely painful, and incurable pancreatic condition, Hereditary Pancreatitis (PRSS1), from which her husband died. She has had trouble with Medicaid eligibility for her children, but, even when they were receiving Medicaid benefits, there were significant barriers to getting needed care. There was only one pediatric gastroenterologist in the state, and that doctor was not familiar with her children's rare condition or the follow-up care they needed after their highly specialized surgery at the University of Minnesota Children's Hospital. At one point, the children's primary care pediatrician told the Medicaid agency that he could not responsibly treat the children without assistance from specialists, but even then it was difficult to get state approval for specialty treatment out of state.

A case from Colorado illustrates some of the problems with Medicaid denials of service and poor communication between Medicaid-waiver administrators and families. Stacy lives with her 7-year-old son, Noah, who suffered oxygen deprivation at birth, resulting in Spastic Quadriplegia Cerebral Palsy. He cannot sit, stand, walk, talk or self-feed, so requires 24- hour assistance. In addition, he needs wheelchairs, adaptive clothing because of his severe sensory processing disorder, home modifications, and more. Noah is covered by Medicaid, but Stacy had to appeal denials of service almost every time she submitted a request for coverage. Even after a judge found a denial to be inappropriate, the state still withhold services under an "exception to initial decision," which cannot be reviewed by a judge again. Noah is also eligible to receive services under a waiver administered by the Community Centered Boards (CCB), but the process for reimbursement is very opaque and has appeared to be arbitrary or inappropriate. (See this Denver Post article about the CCB's handling of funds.)

Care coordination

One of the more common problems for families of children with complex medical conditions is a lack of care coordination among their child's many health care providers – one of the major issues that the ACE Kids Act seeks to address.

In a 2012 survey, families of children with special health care needs (CSHCN) identified care coordination as their top priority.[5] As noted by the Catalyst Center: "At its best, care coordination is a covered service…that addresses the interrelated medical, social, developmental, behavioral, educational, and financial needs of children and their families. But there is great confusion over who is responsible for providing care coordination services, who should pay for them, and how to get reimbursed for such services."

As a result of this confusion, families of children with complex medical conditions sometimes fail to get any care-coordination services at all, and sometimes get it from too many sources, such as hospitals, insurance companies, and public agencies. Thus, they may end up "coordinating the coordinators." Families of children with complex medical conditions often find that their child's multiple physicians and other providers are not communicating, or not doing so effectively, leading to gaps in care, inappropriate treatment, or duplicative appointments, assessments and tests (which needlessly cause stress for the child and cost time and money for parents).

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[5] Catalyst Center webpage introducing the publication *The Care Coordination Conundrum and Children and Youth with Special Health Care Needs*.

Although some Medicaid agencies and managed care organizations claim to provide care coordination, families may not really be receiving it, or the services they get are inadequate. For example, some care coordinators are not well-trained, do not have the capacity to help families with limited English proficiency, and/or lack knowledge about community services, Medicaid waiver programs, specialty clinics, or other resources that could improve a child's treatment or be useful to families.[6] Although pediatricians, children's hospitals and other providers may be willing to coordinate care, they generally are not reimbursed for the staff time required so are limited in their capacity to do so.

That said, there are some effective care coordination programs. In Rhode Island, a partnership of state agencies, the state's chapter of the American Academy of Pediatrics, the Rhode Island Parent Information Network/Family Voices, and the Neighborhood Health Plan of Rhode Island developed the Pediatric Practice Enhancement Project (PPEP), through which parents of children with special health care needs are employed to help patients' families at primary- and specialty-care sites. Like Family-to-Family Health Information Centers, the PPEP model is based on the concept that parents who have faced the challenges of raising children with special needs are best equipped to help other families of CYSHCN. The parent coordinators help families access and coordinate specialty services, link to other community resources, navigate the complicated health care system, and overcome barriers to care. Placing parent consultants directly in the offices of practitioners also assists the physicians and their staff by identifying resources and support services that will help patients and their families. PPEP promotes a

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[6] Family-to-Family Health Information Centers (F2Fs) help families to get this type of information, and help them develop skills to enhance communication with their children's health care providers and coordinate their care.

"medical-home" model of care, where the primary care or other provider serves as the hub for coordinating the child's care. The PPEP model has also been used in Delaware.[7]

Some resources about other care-coordination models and medical homes are listed at the end of this testimony.

COMMENTS ON THE DISCUSSION DRAFT

As illustrated above, there are serious obstacles to getting necessary care for children with medically complex conditions in the Medicaid program. Therefore, Family Voices wholeheartedly supports the goals of the ACE Kids Act, including better coordination of care for children with complex medical conditions, and improved access to the full range of medical and support services they need, including services in other states.

The committee discussion draft would give states the option to provide "health home services" to children with complex medical conditions. "Health home services" are defined as "comprehensive and timely, high quality services" provided by a "designated provider or a team of health care professionals, that include, at a minimum: comprehensive care management; care coordination and health promotion; comprehensive transitional care, including appropriate follow-up, from inpatient to other settings; patient and family support; connection to community and social support services; use of health information technology to link services, as feasible and appropriate; and coordinating access to the full range of pediatric specialty and subspecialty medical services, including services from out-of-State providers, as medically necessary."

Medicaid payment for the health home services described in the bill would go a long way toward addressing some of the obstacles to appropriate and timely care that are discussed above. Care management, care coordination, and transitional care would help to ensure that children get

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[7] The Commonwealth Fund published a case study of the PPEP in 2009.

the services they need while avoiding redundancy. Patient and family support, with referral to community and social support services, would help to ensure that families get important non-medical services and supports. The use of health information technology to link services could help to improve communication among a child's multiple health care providers. And coordinating access to the full range of medically necessary pediatric specialty and subspecialty medical services, including services from out-of-state providers, would help to ensure that children receive the most appropriate services, even if the providers are out-of-state.

Since access to out-of-state care has posed a significant problem for some children, we are very pleased that the discussion draft would require the Administrator of the Centers for Medicare and Medicaid Services (CMS) to develop best practices for using out-of-state providers in both emergency and non-emergency situations. We also appreciate the requirement that the Administrator issue a Request for Information to obtain stakeholder input in developing these guidelines.

Although we think the discussion draft provides a good start in addressing some of the Medicaid obstacles discussed above, we would like to offer the following comments and suggestions that we think could enhance the positive impact of the legislation. We would welcome the opportunity to work with the committee staff to develop specific language related to these issues.

Recommendations

Qualification standards for health homes. The health homes provision of the Affordable Care Act (ACA), §1945 of the Social Security Act, from which much of the language of proposed §1947 is based, requires the Secretary of Health and Human Services to establish standards for qualification as a health home. The discussion draft, however, does not include a parallel provision. The draft bill (pp. 10-11) would require only that a “designated provider” “be determined by the state to be qualified ... on the basis of documentation evidencing that the [provider] has the systems and infrastructure in place to provide health home services.”

Some of the problems with care coordination in Medicaid arise from the fact that the individuals and organizations responsible for providing coordination services are not always well-trained, knowledgeable about community resources available, or equipped to provide translation services or work with effectively with families from other cultures. We believe that Medicaid funds would be better spent if health homes were required to meet clear standards with respect to training of personnel, record-keeping, communication procedures, linguistic and cultural competence, and other aspects of the “systems and infrastructure” needed to provide quality health home services. ***Therefore, we recommend that the ACE Kids Act require the Secretary or the CMS Administrator to develop qualification standards for health home providers. These standards should include a requirement that the health home have pediatric expertise. Further, these standards should be developed through the issuance of a Request for Information to ensure appropriate stakeholder input.***

Coordination with state Family-to-Family Health Information Centers. The staff of Family-to-Family Health Information Centers (F2Fs) are familiar with community resources available to families whose children have medically complex conditions. As parents of CYSHCN , F2F staff can also offer important peer support to families seeking their help. Coordination between health homes and F2Fs would enhance services for families and promote efficient use of federal resources. ***Therefore, we recommend that health homes be required to work with their state's federally funded Family-to-Family Health Information Center.***[8]

Family Engagement. Families have critical insights about how institutions and systems can best serve their children, and do so more efficiently. Family Voices believes that there should be "nothing for families without families."[9] ***Therefore, we also recommend that states, in developing their health home State Plan Amendments, and individual health homes, as they develop and implement their policies and procedures, be required to seek meaningful engagement of families of children with complex medical conditions, youth with complex medical conditions, and organizations that represent these families and youth.***

Hospital referrals and education about availability of health home services. The draft bill (pp. 4-5) requires states to include in their health-home State Plan Amendment a description of the state's process for educating providers about the availability of health homes for children with medically complex conditions, including the process by which such providers can refer children to designated health home providers. ***We agree with this requirement, but recommend that states also be required to describe a process by which they will educate families, in a linguistically and culturally competent manner, and appropriate social service agencies about the availability of health home services. In addition, states should be required to educate***

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[8] We also recommend that Congress extend funding for Family-to-Family Health Information Centers (F2Fs) beyond FY 2017.

[9] One of Family Voices' main missions is the promotion of family engagement, with the aim of improving institutional and government policies affecting CYSHCN and their families. Through a series of cooperative agreements with the Maternal and Child Health Bureau, Family Voices has run the National Center for Family/Professional Partnerships (NCFPP) for 17 years. The NCFPP, among other things, provides technical assistance and training to the nation's 51 Family-to-Family Health Information Centers (F2Fs). The NCFPP and the F2Fs train parents and professionals to become more effective partners in the treatment of CYSHCN, and train parents and youth of diverse backgrounds to meaningfully engage with policymakers at the individual, community, state and federal levels. (Please see the relevant attachments.)

providers and families of children with medically complex conditions about the state's Family-to-Family Health Information Center.

Adoption of best practices for access to out-of-state services. The draft bill (p. 5) provides that states taking up the health home option "consider" adopting best practices for providing access to out-of-state providers for children with medically complex conditions. ***We recommend that states taking up the health home option be required to adopt the best practices developed by the Administrator for providing access to out-of-state providers. (In fact, we recommend that all states be required to adopt these best practices, and that they be applicable to all Medicaid beneficiaries, so that no Medicaid beneficiaries are denied access to medically necessary out-of-state care.)***

Data collection. The draft (p. 6) requires designated health home providers to report quality measures to the state in accordance with guidance provided by the Administrator. ***We recommend that the Administrator be required to seek stakeholder input in developing these quality measures through the issuance of a Request for Information.***

Definition of "Child with Medically Complex Condition" (p. 7-9)

We are concerned that the definition of a child with a medically complex condition may be too narrow, particularly since a state can further narrow it. The proposed definition would not include children with a **single** but very serious or complex condition, such as severe epilepsy, mental illness, or a traumatic brain injury, that does not also affect two body systems or impede physical or cognitive function. ***We recommend that the committee consult with stakeholders to consider whether this definition should be broadened.***

Freedom of provider choice. The draft bill (p. 12) seeks to protect beneficiary choice of Medicaid providers. We strongly agree with this provision, given the importance of having a continuous relationship with appropriate subspecialists who are familiar with a child's (often rare or unique) condition, and have relationships with the child and child's family. ***We recommend that language be added to this or another appropriate section to make it clear that a child may not be assigned to or be required to select a health home.***

General comment

As we interpret the discussion draft, a health home would not necessarily be providing any health services to the child. Nor would it be required to have any pediatric expertise. In fact, unless there are a number of health homes to choose from, a child seeking health home services might need to get them from a type of provider totally unrelated to his or her condition. For example, a family whose child has spina bifida might be receiving health home services from a community mental health center. Although such a situation would not necessarily pose a problem, we urge the committee to give further thought to the relationship between a child's health home and health care providers. The committee might want to consider ways that the Medicaid program can be used to support the "**medical home"** model. As defined on the website of the National Center for Medical Home Implementation, a "medical home is an approach to providing comprehensive primary care that facilitates partnerships between patients, clinicians, medical staff, and families. It extends beyond the four walls of a clinical practice to include specialty care, educational services, family support and more." In fact, the US Department of Health and Human Services' Healthy People 2020 goals and objectives state that "all children with special health care needs will receive regular ongoing comprehensive care within a medical home."

On behalf of Family Voices, I would like to thank the Chairman, Ranking Member, and Subcommittee Members for the opportunity to testify about the important issues addressed in the

ACE Kids Act. We would be happy to work with the Committee staff to develop specific language related to any of our recommendations, or to help in any other way we can to ensure that children with complex medical conditions receive timely and appropriate Medicaid services.

Family Voices contact:
Janis Guerney
Public Policy Co-Director
jguerney@familyvoices.org
202/546-0558

REFERENCES

Medical debt

Payer of Last Resort: Medical Debt and Financial Hardship Among Families Raising Children and Youth with Special Health Care Needs, from the Catalyst Center

Out-of-state care

Interstate Medicaid Billing Problems: Helping Medicaid Beneficiaries Who Get Care Out of State, from Families USA

Care coordination

Care Coordination, from the Catalyst Center (examples of care coordination models funded through the Maternal and Child Health Block Grant and Medicaid)

The Care Coordination Conundrum and Children and Youth with Special Health Care Needs

Care Coordination in a Statewide System of Care: Financing Models and Payment Strategies, from the Catalyst Center

Health homes and Medical Homes

National Center for Medical Home Implementation (MCHB-funded, American Academy of Pediatrics)

Building a Medical Home for Children, from HRSA

Data Resource Center for Child and Adolescent Health Medical Home Portal

Medicaid Health Homes Still a Work in Progress, from the Commonwealth Fund, Washington Health Policy Week in Review, June 27, 2016

What's in a Name? Medical Home vs. Health Home vs. PCMH, from Greenway Health, LLC, blog post of Sept. 5, 2013

The Difference Between Patient-Centered Medical Homes & Medicaid Health Homes (In Plain English), from eCaring, April 29, 2013

Medical Home V. Health Home – Confused?, from Open Minds

ATTACHMENTS

1. Family Voices & Family-to-Family Health Information Centers
2. Family-to-Family Health Information Centers
3. The Importance of Medicaid to Children and Youth with Special Health Care Needs
4. Family Voices Awarded New 3-Year Cooperative Agreement as the National Center for Family/Professional Partnerships

Family Voices & Family-to-Family Health Information Centers

Introduction

Family Voices is entering its 24th year as the national, cross disability, family-led organization dedicated to "*keeping families at the center of children's health care.*" This includes serving in its 18th year as the National Center for Family Professional Partnerships (NCFPP) (www.fv-ncfpp.org), funded by the Health Resources and Services Administration's (HRSA's) Maternal and Child Health Bureau (MCHB). Family Voices, in partnership with HRSA and the Centers for Medicare and Medicaid Services, created and piloted the model for what are now the 51 HRSA-funded Family-to-Family Health Information Centers (F2Fs). Over the last decade, Family Voices has supported the development and strengthening of vital, connected, family leadership in the states, through the network of F2Fs and Family Voices State Affiliate Organizations (SAOs).[10]

Over time, Family Voices has also partnered extensively with many professional organizations helping them engage families as partners. In addition to the NCFPP project, Family Voices this year has secured funded projects engaging families as partners with the following:

- American Academy of Pediatrics (AAP),
- Centers for Disease Control,
- Association of Maternal and Child Health Programs,
- Association of University Centers on Disability,
- Patient Centered Outcomes Research Institute (PCORI),
- Child and Adolescent Health Measurement Initiative,
- American Association on Health and Disability,
- National Conference of State Legislatures,
- National Academy for State Health Policy,
- Association for State and Territorial Health Officials, and
- Society of General Internal Medicine.

Each of these projects extends the impact and priorities of HRSA and MCHB. In the new NCFPP project, Family Voices is partnering with the Statewide Parent Advocacy Network (SPAN) of New Jersey, which serves as the statewide F2F and FV SAO, as well as the Parent Training and Information Center, Parent to Parent USA affiliate, and a chapter of the Federation of Families for Children's Mental Health. SPAN also houses the National Center for Parent Information and Resources and the National Resources for Access, Independence, Self-Advocacy and Employment (RAISE) Transition Technical Assistance Center – projects funded by the US Department of Education.

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[10] F2Fs are the federally-funded and designated organizations that are family-staffed/run to provide support to families of CYSHCN across the six MCHB core outcomes. Family Voices SAOs are family-led organizations are designated by Family Voices, Inc. Each SAO's Board of Directors consists of a majority of parents of CYSHCN (ages birth to 26). The vast majority of F2Fs (80.4%) are also the FV SAO in their state.

Why are F2Fs so important for outcomes?

Parents who advocate effectively on behalf of their child's health care and who have the partnership skills to communicate and work with healthcare providers in meaningful ways report improved health outcomes for their children as a result of that parent involvement. A growing body of evidence demonstrates that parents are more likely to be able to advocate effectively when they are provided with support by peers.

For example, a study of the impact of the ***Rhode Island Pediatric Primary Care Enhancement Project***, a pilot funded by HRSA via Rhode Island's D70 project, found that housing trained parents of CYSHCN in pediatric practices reduced the cost of care from 11-15%, improved appropriate utilization of healthcare services including lowering in-patient utilization, and increased both parent and provider knowledge and satisfaction. The project involved housing trained Family Resource Specialists at primary care practices 20 hours/week to provide support to individual families (including families of children with and without special healthcare needs) in navigating across and advocating in multiple systems. These family leaders also worked with primary care providers on partnering more effectively with families and connecting families to available resources and supports. See "Evaluation of Rhode Island's Pediatric Primary Care Enhancement Project," http://rimed.org/medhealthri/2009-07-253.pdf.

In a more recent study, a randomized trial revealed that trained Parent Mentors (PMs) are significantly more effective than traditional Medicaid and Children's Health Insurance Program methods in insuring uninsured minority children; obtaining insurance faster; renewing coverage; improving access to primary, dental, and specialty care; reducing unmet needs and out-of-pocket costs; achieving parental satisfaction and care quality; and sustaining long-term coverage. PMs also are inexpensive, costing $53/child/month, and save $6,045.22/insured child. The study, led by Medica Research Institute Distinguished Chair in Health Policy Research Glenn Flores, is the first to assess the effectiveness of PMs in insuring uninsured minority children. PMs are a special category of community health workers who have children with particular health conditions and risks. They leverage their relevant experience, along with additional training, to assist, counsel, and support other parents of children with the same health conditions and risks, including assisting families with insurance applications, retaining coverage, medical homes, and social needs, a model that sounds remarkably like that of the F2Fs. See www.medicaresearchinstitute.org/files/2114/5875/8554/Pediatrics_Kids_HELP_RCT_Article_3-17-16_DV.pdf.

F2F staff are parents of CYSHCN who have learned how to effectively navigate multiple systems and who are able to share their knowledge and expertise and work with families to develop their advocacy and partnership skills. Ninety-two percent (92%) of families helped by F2Fs report that they are better able to partner with providers and navigate systems as a result of the assistance received, and 90% report increased confidence in their ability to access the services their child and family need.

How do F2Fs Connect Families to Health Insurance and Healthcare Financing?

F2Fs support families across all six MCHB core outcomes for CYSHCN, including access to adequate healthcare financing such as Medicaid, State Children's Health Insurance Program, and private insurers via the Affordable Care Act (ACA) Marketplace.[11] In 2014-2015, F2Fs served 638,713 families on topics

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[11] F2Fs provided 1-1 assistance and training to 43,607 families on medical home, 79,035 families on navigating community-based systems, 67,997 families on partnering with professionals, 24,120 families on screening, and 27,284 families on transition. When you include information provided via listservs and newsletters, the totals are 626,582 (medical home), 662,010 (navigating systems), 650,972 (partnering with professionals), 607,095 (screening), and 610,259 (transition to adult systems of care).

related to health insurance and other healthcare financing via individual assistance, workshops, and dissemination of resources (55,738 via individual assistance and workshops alone), including information from the FV NCFPP monthly blog/Tip Sheets on the ACA and CYSHCN (www.fv-ncfpp.org/blog/). According to most recent data, 48 F2Fs reported engaging in initiatives focused on Medicaid, Medicaid managed care, Medicaid waivers, and Medicaid buy-in programs. In addition to this HRSA-funded work, many F2Fs have secured additional funds to provide ACA information, training, and enrollment assistance to families. Family Voices wrote grants to help nine F2Fs (***Arizona, Colorado, Indiana, Louisiana, Nevada, N. Dakota, Rhode Island, Texas, and Washington State***), receive funding from the National Disability Navigator Resource Collaborator to support individuals with disabilities to access the ACA. Other F2Fs have received funding to serve as ACA navigators individually (e.g., ***Vermont*** Family Network) or as members of coalitions (e.g., ***Georgia*** Parent to Parent), with state or CMS-funded navigator grants, while others have received foundation funding to assist with enrollment (e.g., Statewide Parent Advocacy Network of ***NJ***). Some F2Fs have also utilized their expertise to build the capacity of the funded navigators to be able to understand the special healthcare financing issues faced by families of CYSHCN as well as other healthcare financing resources above and beyond the ACA (e.g., State Catastrophic Illness in Children Relief Funds) by providing training to ACA navigators, Federally Qualified Health Center (FQHC) enrollment assisters, and others. Finally, some F2Fs have partnered with health advocacy coalitions to develop and disseminate videos about the ACA for diverse families (for example, www.spanadvocacy.org/content/affordable-care-act-helps-connect-new-jerseyans-health-care).

How do F2Fs Reach and Support the Most Underserved Families?

F2Fs provide direct support through free one-to-one assistance and training. From June 1, 2014, through May 31, 2015, F2Fs assisted and trained 155,950 families (unduplicated) and 74,225 professionals (unduplicated). Almost 40% of the families served by F2Fs reported that they were non-white, while almost 30% were Hispanic/Latina. F2Fs reach families of diverse backgrounds in many ways—hosting support groups and leadership conferences for Spanish-speaking participants, facilitating focus groups to create culturally competent materials, participating in community meetings serving diverse communities, and partnering with community brokers. F2Fs also help develop the leadership skills of diverse families, which is a major focus of the new NCFPP project. F2Fs partner with agencies that serve the most underserved families such as FQHCs. Thirty-seven (37) F2Fs indicated significant involvement with community health/rural health agencies, and 21 F2Fs reported collaboration with FQHCs on specific initiatives in 2014-2015. For example, in ***Georgia***, the F2F houses regional coordinators in clinics serving underserved populations. After the family sees the doctor, the regional coordinator connects the family to local resources, matches them to another family for emotional support, and provides them with information. In ***NJ***, the F2F facilitated a State Implementation Grant on Innovative Evidence-Based Practices that partnered with three FQHCs in low income, high immigrant communities. Trained Family Resource Specialists provided training to the FQHCs to improve their screening, medical home-ness, and transition to adult life services, and training, leadership development, and support to immigrant, limited English proficient parents served by those FQHCs leading to statistically significant improvements in outcomes. Trained immigrant parent leaders continue to work with the FQHCs to provide ongoing support to families of CYSHCN, and several of the FQHCs continue to facilitate ongoing parent support groups for families of CYSHCN in their practice. In addition, the NJ Primary Care Association is a member of the Statewide Community of Care Consortium for CYSHCN and has invited the F2F to present at its annual conference several times.

Family Voices supports this work through the NCFPP and with other resources, including funding seven F2Fs as Polly Arango Mentoring Initiative grantees and members of a learning collaborative around preparing and supporting diverse parent leaders (private funds); funding two F2Fs as PCORI grantees around health promotion for diverse families (PCORI funds); identifying exemplary/promising practices in serving diverse families and organizations disseminating information about those practices (NCFPP); and many educational opportunities such as webinars, resource materials and conferences (NCFPP and NCFPP supplement).

How do F2Fs Enhance Quality, Medical Home, Patient/Family-Centered Care, and Impact Delivery System Reform?

In 2014-2015, F2Fs reported active engagement in state initiatives focused on family-centered care (43), medical home (42), and quality improvement (27). For example, the ***Utah*** F2F developed a Medical Home Portal for families, clinicians, and allied healthcare professionals. The content, tools, and resources were vetted by a team that included parent staff from the F2F, the University of Utah Department of Pediatrics, Title V, and pediatricians (www.medicalhomeportal.org/). In ***West Virginia***, the F2F is working with the state to improve the quality of service delivery related to Care Coordination and the Medical Home through redesigning state policies and procedures for CYSHCN, assisting with level of needs assessment, attending home visits, supporting families in clinics, and helping with the assessment and care plan development. NCFPP supported engagement of 14 F2F/professional teams in collaborative quality improvement efforts via its ABCs of Quality Improvement intensive training webinar course, in partnership with the National Institute for Children's Health Quality (NICHQ). (www.fv-ncfpp.org/activities/quality-improvement/). Overall, in 2014-2015, 23 F2Fs reported significant involvement in NICHQ Learning Collaboratives, and 28 reported significant involvement overall with health care quality initiatives or organizations.

Family Voices encourages these initiatives at the state level and also provides many opportunities for family leaders from the states to participate in national systems level partnerships. Examples in the last two years include:

- Development of the Family-Centered Care Assessment tool (FCCA, www.fv-ncfpp.org/activities/fcca/) and participation in its validation study;
- Participation in four Agency for Healthcare Research and Quality measurement development projects around transition, foster care, care coordination, asthma and complex care;
- Participation as liaisons to the AAP Council on Children with Disabilities and the AAP Committee on Quality Improvement;
- Representing families on the National Emergency Medical Services Advisory Council;
- Participation in the development and testing of questions for the National Surveys of Children's Health;
- Assisting the Child and Adolescent Measurement Initiative with the design and development of the Data Resource Center, a public website disseminating information from the surveys;
- Providing input to researchers around Adverse Childhood Experiences (ACEs); and
- Testifying about family needs and experience before government hearings, among others.

Conclusion

Approximately 8.8 million (one in five) families in the US have a least one child under the age of 18 with a special heath care need. Of these, about 3 million families report not being able to easily access community-based services due to eligibility issues, services not available, problems getting appointments, costs of services, lack of information, and other difficulties. F2Fs exist in every state and the District of Columbia to provide assistance to help these families and professionals address these critical issues. F2Fs are staffed by family members who have first-hand knowledge and training in navigating the maze of health care services for CYSHCN. With the support of Family Voices and the NCFPP, F2Fs help families through free one-to-one assistance and training that gives families information and advice, bolsters their confidence, and shares tools that help them more effectively communicate with providers and advocate for their children; disseminate information via fact sheets, manuals, and toolkits, newsletters/e-newsletters, websites, and other social media; and partner at the systems level to improve access to quality of services, by serving as family faculty to healthcare providers, participating on health clinic, hospital, and health maintenance organization advisory boards, working with state agencies on policies to ensure that they effectively meet the needs of diverse families and participating in national level partnership activities to improve policies and systems. Outcomes research provides evidence of the value of such participation at all levels of health care. HRSA's investment in developing strong "family voices" for CYSHCN has already had an impact on other systems and individuals and has enormous potential to contribute to all of HRSA's strategic priorities.

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FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS (F2Fs)

- Throughout the US, there are approximately 14.6 million children and youth with special health care needs (CYSHCN), constituting nearly 20 percent of the child population. More than one in five households with children has at least one child with special health care needs. Out of insured CYSHCN, 34.3 percent have families who report their insurance is inadequate to meet their needs.

- It is very difficult for families to figure out how to finance their children's care, given the great expense and complexity of potential funding sources – private insurance, Medicaid, CHIP, state Maternal and Child Health programs, the school system – each with different eligibility and coverage criteria.

- Family-to-Family Health Information Centers (F2Fs) help families of children/youth with special health care needs learn how to navigate the complex health care system and to make informed choices about health care in order to promote good treatment decisions, cost-effectiveness and improved health outcomes.

- There is one F2F in every state and the District of Columbia, each of which receives $95,700 per year in federal grants. Despite their shoe-string budgets, F2Fs trained and assisted over one million families and 376,000 health professionals in 2013-2014.

- F2Fs also provide leadership and training for health care providers and policymakers to work toward the goal of a family-centered "medical home" for every child.

- F2Fs are staffed by families of CYSHCN who have extensive personal experience and professional training in accessing and financing health care for CYSHCN.

- The F2F grant program, administered by the Maternal and Child Health Bureau, was established with bipartisan support by the Family Opportunity Act, part of the Deficit Reduction Act of 2005, and was directly funded through FY 2009. Through subsequent laws, most recently the Medicare Access and CHIP Reauthorization Act of 2015, the F2F program has been funded through FY 2017 at the level of $5 million per year. (No appropriations are necessary.)

- A CMS-funded outside evaluation of F2F HICs noted: "The accomplishments of these Grantees are impressive, particularly in light of their modest grant funding," and "Through their work to promote family-centered, culturally competent, and linguistically appropriate care and medical homes for CYSHCN, [F2Fs] are contributing to improvements in the quality of health care."

- Said one parent, "Since I now know about Family Voices, my life has changed a lot as far as being strong to make sure my daughter's needs are met. This is a huge change for me."

For national and state-specific information about F2F HICs, see http://www.fv-ncfpp.org/f2fhic/about_f2fhic/,
*or contact Janis Guerney (**202-546-0558** / jguerney@familyvoices.org)or*
*Brooke Lehmann (**202-841-4341** /blehmann@familyvoices.org).*

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THE IMPORTANCE OF MEDICAID TO CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS OR DISABILITIES

Medicaid is a vital program for children and youth with special health care needs (CYSHCN) – children who have any of a broad range of chronic illnesses and/or disabilities (e.g., *cerebral palsy, epilepsy, diabetes, autism).* Approximately 11.2 million children in the United States – or 15.1 percent of all U.S. children – have special health care needs. Over 44 percent of these children rely in whole or part on Medicaid or CHIP to cover the costs of their care.

Nearly 4 million CYSHCN – 35.9 percent -- rely completely on public insurance to get the services they need. Another 8.2 percent have a combination of private and public insurance. In those cases, Medicaid helps families pay for out-of-pocket costs, and may serve as "wrap-around" coverage to supply services or devices not covered by their private plans. For example, some medical equipment and assistive devices (such as hearing aids) may not be covered under traditional insurance plans but are available through Medicaid.

Accordingly, Medicaid can save families from bankruptcy that might otherwise result from high medical bills. In many cases, it also allows parents to continue working by supplying caretaking services for their children.

In addition, Medicaid helps to prevent or ameliorate disabilities, since children on Medicaid have access to Early and Periodic Screening, Diagnosis and Treatment (EPSDT). Early screening and diagnosis means that developmental or health problems can be identified early in a child's life, and necessary treatment can be provided before a condition develops or becomes more severe. As a result, some children can avoid the need for special education services.

If not for Medicaid --

- Santina, a 13-year old in Pennsylvania with Rett Syndrome and epilepsy, could lose access to her medication. And, her single mother would probably have to quit her two jobs if Medicaid's safety net were not there to provide a caretaker for her daughter.
- The family of 8-year old Joshua – whose life-saving liver transplant was paid for by Oregon Medicaid -- would not have the means to pay for the 22 medications he must take every day.
- Jason -- a 3-year-old from Ohio who has developmental delays that leave him unable to speak, walk, or use his hands in a coordinated fashion -- would lose the early intervention, speech, occupational, and physical therapies that will one day allow him to walk, speak and use his hands.

In short, millions of vulnerable children and their families rely on Medicaid to help them obtain and pay for critical medical care and related services.

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June 13, 2016

Family Voices Awarded New 3-Year Cooperative Agreement as the National Center for Family/Professional Partnerships

Family Voices is pleased to announce the award of a new three-year a new three-year cooperative agreement from the Maternal and Child Health Bureau to serve as the National Center for Family Professional Partnerships (NCFPP). The new project period will be June 2016 through May 2019. The project will focus on supporting and developing family and youth leadership, particularly the leadership of racially and ethnically diverse families of CYSHCN. This agreement will promote the engagement of diverse families in meaningful ways in systems level activities and encourage the reduction of health disparities through family engagement. The Statewide Parent Advocacy Network (SPAN), which serves as the Family-to-Family Health Information Centers (F2F) and Family Voices State Affiliate (FV SAO) in New Jersey, is partnering with Family Voices in this work, bringing their extensive expertise and experience in family and youth leadership training, especially for racially and ethnically diverse minority families.

Family Voices is entering its 24th year as the national cross disability family-led organization dedicated to ensuring that families are kept at the center of children's health care. Our belief is strong that this principle is essential to improving the health and quality of life for all children including children and youth with special health care needs. As the NCFPP, Family Voices has led the development and support of vital, connected, family leadership in the states, including MCHB funded Family-to-Family Health Information Centers (F2F HICs) and Family Voices State Affiliate Organizations (SAOs). As the NCFPP we have developed vital partnerships with multiple partners key to children's health, other national centers and key stakeholder groups. Family Voices is proud to have played a role in the implementation of a vigorous network of state level F2F HICs, from a pilot program of 6 centers in 2003 to the successful establishment of 51 current active centers in all states and the District of Columbia. With this new NCFPP funding we have the opportunity to move family leader engagement to a new level and to expand the opportunities for all families, particularly those from underserved communities, to impact the very systems that are designed to support them.

Under this project, the NCFPP will:

- Provide assistance and support to the HRSA-funded F2F HICs and other MCHB investments on the topics of family and youth engagement and cultural and linguistic competence; and
- Implement family and youth leadership development and training activities, specifically for racially and ethnically diverse minority families of CYSHCN and YSHCN, to help them (a) increase their knowledge, leadership skills and abilities in family engagement methodologies; (b) stay connected to other family leaders across the nation; and (c) receive ongoing training and support.

Over the coming weeks and months, we will be sharing specific project information and opportunities for training and technical assistance to family leaders and MCHB staff. We look forward to engaging with you around this exciting work which focuses on MCHB's priority of targeting ways to improve the health and quality of life for all CYSHCN, especially children from diverse, racial and ethnic communities.