



FAMILY VOICES[®]

Washington DC Update
July 19, 2019

Greetings from Washington!

The big news this week: The House Committee on Energy & Commerce favorably reported out legislation to extend funding for Family-to-Family Health Information Centers for four more years (through 2023) at the current funding level of \$6 million per year. The administration proposes to revamp rules about how states ensure equal access to care for Medicaid beneficiaries. The administration announced initiatives to promote home kidney dialysis and to increase the number of kidney transplants.

REMINDERS: The Centers for Medicare and Medicaid Services (CMS) has issued the Notice of Funding Opportunity (NOFO) for the Federally-facilitated Exchange (FFE) Navigator Program, and the [Application Link](#) is now live to apply to be a “Certified Designated Organization” to assist people with getting insurance through the Affordable Care Act (ACA). (See the “ACA” section below.)

UPCOMING WEBINARS AND CALLS

NEW [Final Conscience Regulation: Does the New HHS Rule Promote Injustice?](#)

Friday, July 19, 2019 1:00-2:00 pm ET

National Health Law Program

NEW [Culturally Competent Direct Care: Meeting The LTSS Needs Of Diverse Dually Eligible Beneficiaries](#)

Thursday, July 25, 12:30-2:00 pm ET

Resources for Integrated Care

NEW [TRICARE Webinar on TRICARE Coverage after Retirement](#)

Thursday, July 25, 1:00-2:00 pm ET

TRICARE; Military OneSource

NEW [Evidence for the Impact of Money Follows the Person \(MFP\)](#)

Thursday, July 25, 2:00-3:30 pm ET

Brandeis University

Email: clpolicy@brandeis.edu if you have any questions or need any further accommodations.

NEW [Growth and Development: Capitalize on New Business Opportunities](#)

Wednesday, July 31, 12:30-1:30 ET

Administration for Community Living HCBS Business Acumen Center

Topic: How to assess your organization’s financial position to move into new contract arrangements and what you specifically need to focus on to work with managed care organizations.

NEW [Technical Assistance webinar: HRSA Early Hearing Detection and Intervention \(EHDI\) Program Notice of Funding Opportunity \(NOFO\)](#) [link at below date, time]

Wednesday, July 31, 2:00 pm ET

Health Resources and Services Administration (HRSA)

Call-In Number: 1-888-889-2042

Participant Code: 1398484

NEW [Question and Answer Session: Disability-Competent Care Conversation on Access with ADANN \(Americans with Disabilities Act National Network\)](#)

Wednesday, July 31, 2:00-2:30 pm ET

The Lewin Group, in collaboration with ADANN

NEW - SERIES: #ABLEtoSave Awareness Campaign

ABLE National Resource Center

First webinar: [Welcome to #ABLEtoSave Month: An Orientation on What You Need to Know About ABLE](#)

Thursday, August 1, 2:00-3:00 pm ET

Future webinars:

- Week 1: August 8: Opening an ABLE Account: Key Decisions for Success
- Week 2: August 15: ABLE Best Practices and Action Steps for Family Members and Supporters (Circle of Support)
- Week 3: August 22: ABLE Best Practices for Working-Age Adults
- Week 4: August 29: Celebrating All the Ways You are ABLE: Announcing Winners from #ABLEtoSave Video Contest and Next Steps!

CONGRESS

F2F and Other Health Bills Marked Up by House Committee

On Wednesday, July 17, the House Energy & Commerce Committee favorably reported out legislation that includes a provision to **extend F2F funding for four more years** – through FY 2023. The committee’s Health Subcommittee had reported out the legislation last week. (See “Background,” below.) The F2F provision is included in Section 103 of an amended version of [H.R. 2328](#), which was further amended during the committee’s 5-hour “[markup](#)” of 26 different bills. Other bills reported out of the committee included an amended version of the Autism CARES Act, and bills to reauthorize the Lifespan Respite Care program, the Emergency Medical Services for Children (EMSC) program, the newborn screening program, and the Patient-Centered Outcomes Research Institute (PCORI), among others. In addition, the committee reported out a bill to address the problem of [surprise medical bills](#), and to [increase Medicaid funding for the territories](#), with additional oversight for Puerto Rico. See [House Committee Advances Bill to Sustain Medicaid Programs in the Territories and Avoid Deep, Harmful Cuts](#) (blog of the Georgetown Center for Children and Families, 7/15/19 [written prior to

amendments]. See the [Chairman’s press release](#) and [briefing memorandum](#) for more details and links to bill text. It is not clear when any of these bills will be taken up by the full House.

As yet, no action has been taken yet on the bipartisan **Senate bill** that would extend F2F funding for five years (S. 1647). Family Voices will be working to get cosponsors for that legislation, which was introduced by Senators Chuck Grassley (R-IA) and Robert Menendez (D-NJ).

Background. The 4-year funding extension for F2Fs reflects a bipartisan compromise. The free-standing F2F bill (H.R. 2822), introduced by Reps. Mikie Sherrill (D-NJ) and Fred Upton (R-MI), would have extended the program for five more years, while a bill (H.R. 2700) offered by the Health Subcommittee’s Republican Ranking Member Michael Burgess (R-TX) would have extended the F2F program (and other programs) for only one more year. The same 4-year funding extension was provided for several other popular public health programs, including the Community Health Center Fund, the National Health Service Corps, the Special Diabetes Program and the Special Diabetes Program for Indians. Like the F2F program, these other “public health extenders” are automatically funded when they are reauthorized. Some other programs that were reauthorized (such as Lifespan Respite and EMSC) must get funding through the separate appropriations process.

Dr. Christina Bethell Testifies on ACEs before House Committee

Kudos to CAHMI’s Dr. Christina Bethell for her recent testimony before the House Committee on Oversight and Reform on Adverse Childhood Experiences (ACEs) science and childhood trauma:

["Identifying, Preventing, and Treating Childhood Trauma: A Pervasive Public Health Issue that Needs Greater Federal Attention"](#) ACEs and childhood trauma have been a key focus for Dr. Bethell and CAHMI. According to the [ACEs Connection blog](#):

Testimony by one of the nation's leading researchers on ACEs science, [Dr. Christina Bethell](#), a professor at Johns Hopkins University, will draw upon state information on ACEs prevalence and key outcomes for children and adults.

To watch the committee hearing click [here](#). Dr. Bethell’s testimony starts at 1 hour and 34 minutes. She also responds to questions throughout the rest of the hearing.

In preparation for this hearing, CAHMI has created [individual state fact sheets](#) on ACEs prevalence using 2016-2017 NSCH (National Survey of Children’s Health) data and recent data from the Behavioral Risk Factor Surveillance Survey (BRFSS).

MEDICAID NEWS, INFORMATION, AND RESOURCES

Administration Proposal to Rescind Current Rule on Monitoring Access to Fee-for-Service Medicaid Services

On July 11, the Centers for Medicare and Medicaid Services (CMS) issued a [Notice of Proposed Rulemaking](#) to rescind the current regulations implementing the Medicaid law’s “equal access” requirement, which requires that states “assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area. At the same time, the agency issued [an informational bulletin to state Medicaid officials](#) “to remind them of their ongoing statutory responsibilities to ensure

appropriate access to care for beneficiaries,” and to announce plans to develop alternative methods to monitor access. The agency plans to work with state and federal stakeholders to “identify measures and benchmarks and data that may be used as common access indicators across fee-for-service, managed care and home and community based waivers.” The current regulations, issued in 2015, govern only access to Medicaid services provided on a fee-for-service basis, as opposed to those provided under managed care arrangements, which are governed under other regulations. See the [CMS press release](#) for more details.

New Report on Potential Impact on Children of Medicaid Block Grants or Per Capita Caps

On July 17, Avalere Health (a consulting firm) issued a report, [Capped Funding Policies Could Reduce Funding for Children Covered by Medicaid](#). The report is discussed in a blog from the Georgetown Center for Children and Families - [New Study Finds Medicaid Per Capita Caps and Block Grants Would Lead to Deep Cuts to Children’s Coverage and Access](#) (7/17/19).

WORTH REPEATING: [Informational Bulletin on Temporary Census Income and Medicaid and CHIP Eligibility](#)

Among community members hired to conduct the 2020 Decennial Census will be many low-income individuals. On July 3, the Centers for Medicaid and CHIP Services (CMCS) issued an [Informational Bulletin](#) (CIB) intended to help states protect these census workers and their families from losing eligibility for Medicaid or CHIP as a result of the income they receive from their employment by the Census Bureau. The CIB describes existing authorities states may use to exclude, or minimize the impact of, income from temporary Census Bureau employment (“temporary census income”) on Medicaid and CHIP eligibility.

WORTH REPEATING: [Joint Informational Bulletin to States and School Systems on Addressing Mental Health and Substance Use Issues in Schools](#)

From the [July 8 Medicaid Bulletin](#) and [SAMHSA Publications](#): On July 8, the Centers for Medicare & Medicaid Services (CMS) and the Substance Abuse and Mental Health Services Administration (SAMHSA) issued a [Joint Informational Bulletin](#) that describes Medicaid mandatory and optional state plan benefits and other Medicaid authorities that states may use to cover mental illness and substance-use-related treatment services delivered to eligible children in school-based settings. The Bulletin also provides states and school systems with best practices and information about resources that will facilitate implementation of quality, evidence-based, comprehensive mental illness and substance use related services for students.

MEDICAID WAIVERS

Reminder:

- Approved and pending Medicaid waiver applications can be found on [Medicaid.gov](#).
- The Kaiser Family Foundation regularly updates its state-by-state §1115 [Medicaid Waiver Tracker](#), and also provides related waiver [resources](#) and [definitions](#).

AFFORDABLE CARE ACT – NEWS, INFORMATION, AND RESOURCES

WORTH REPEATING:

- **Notice of Funding Opportunity for Navigator Grants. Closing date: 7/22/19**
The Centers for Medicare and Medicaid Services (CMS) issued a Notice of Funding Opportunity (NOFO) for the Federally-facilitated Exchange (FFE) Navigator Program, which funds Navigator Organizations to provide in-person, enrollment assistance for individuals seeking health coverage. To view the Notice of Funding Opportunity (NOFO), go to <http://www.grants.gov>, and search for CFDA # 93.332.
- **Certified Application Counselor Designated Organizations - [Live Application Link now available](#). Deadline 9/16/19**
The Centers for Medicare & Medicaid Services (CMS) is inviting organizations that would like to become Certified Application Counselor Designated Organizations (CDOs) to apply during CMS's Open Season, which **ends September 16, 2019**. In the Federally-facilitated Marketplace, CDOs oversee certified application counselors (CACs) who are trained and able to help consumers seeking health coverage options through the Marketplace. **Any organization seeking to provide CAC enrollment assistance to consumers for Plan Year 2020 must be a certified CDO.** In order to be designated as a CDO, you must submit an online application and enter into an agreement with CMS. **If your organization completed the CDO refresh process last year and received a new CDO identification number and a welcome packet, then you do not need to reapply.** CDO Application technical assistance webinar recordings, user guides, and more can be found [here](#). The application itself can be found [here](#). **For additional questions, contact CACQuestions@cms.hhs.gov.** NOTE the webinar for potential CDO applicants listed in the "Upcoming Webinars" section above.

TRICARE

[Traveling Overseas? Know How to Get Care with TRICARE \(7/11/19\)](#)

[Join July 25 TRICARE Webinar on TRICARE Coverage after Retirement \(7/16/19\)](#)

Sign up for TRICARE email updates at www.tricare.mil/subscriptions. Connect with TRICARE on Facebook and Twitter at www.facebook.com/tricare and www.twitter.com/tricare.

OTHER NEWS, INFORMATION, AND RESOURCES

[HHS To Transform Care Delivery for Patients with Chronic Kidney Disease](#)

(CMS Press release, 7/10/19)

The administration will take measures to promote home, rather than center-based, dialysis. In addition, the administration will make efforts to increase the availability of kidneys for transplantation. See [Trump Signs Executive Order Revamping Kidney Care, Organ Transplantation](#) (Washington Post, 7/10/19).

Related:

- [HRSA Fully Supports President Trump's 'Advancing American Kidney Health' Initiative](#)

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- [Kidney Accelerated Placement Project Begins July 18](#)
- [Trump Aims To Shake Up Kidney Care Market \(Politico, 7/8/19\)](#)

RESOURCES:

From the US Department of Health and Human Services (HHS):

Health Resources and Services Administration (HRSA): New Pediatric Care Coordination Curriculum

Grounded in American Academy of Pediatrics policy, a new [Pediatric Care Curriculum](#) provides tools to measure care coordination activities and support continuous quality improvement efforts. Supported with funding from HRSA's Maternal and Child Health Bureau, the curriculum is designed to build capacity among diverse stakeholders, including children and youth with special needs. Learn more at the [National Resource Center for Patient/Family-Centered Medical Home](#).

From the CDC:

[Be an Organization That Advances Health Literacy](#)

WORTH REPEATING:

HHS Office of Civil Rights:

[New Frequently Asked Questions on HIPAA and Health Plans Support Care Coordination and Continuity of Care \(HHS Press release 6/26/19\); HIPAA and Health Plans – Uses and Disclosures for Care Coordination and Continuity of Care:](#)

- Does HIPAA permit one health plan to share protected health information (PHI) about individuals in common with a second health plan for care coordination purposes?
- Does the HIPAA Privacy Rule permit a covered entity to use and disclose PHI to inform individuals about other available health plans that it offers, without the individuals' authorization, if the covered entity received the PHI for a different purpose?

HHS Office of Minority Health:

Free e-learning programs on cultural competency are available from [Think Cultural Health](#), a program of the U.S. Health and Human Services Office of Minority Health that provides health care professionals and others with information, continuing education opportunities, resources, and more to learn about culturally and linguistically appropriate services, or CLAS.

WORTH REPEATING:

From the Consumer Financial Protection Bureau:

[Focus on People with Disabilities](#) Companion Guide, which complements the [Your Money, Your Goals](#) financial empowerment toolkit. The guide includes six fillable and fully accessible tools for how to:

- Set up an Achieving a Better Life Experience (ABLE) Account and build savings
- Pay for assistive technology to achieve independence
- Understand how income from work impacts Social Security Income (SSI)
- Identify financial abuse and exploitation and how to get assistance

From Other Organizations:

From the National Immigration Law Center:

[You Have Rights - Protect Your Health](#) – This document provides an overview for immigrant and mixed-status families of their rights when it comes to **going to the doctor** and **enrolling in health insurance**. (NILC has templates of this document available. If you are interested in a template to tailor and brand for your own organization, please reach out to Kat Lundie (lundie@nilc.org))

From *Clinical Pediatrics*:

[A Step-by-Step Guide to Building a Complex Care Coordination Program in a Small Setting](#). This report from *Clinical Pediatrics* describes a care support project that delivered shared plans of care to providers and families of children with medical complexity.

WORTH REPEATING:

National Academy for State Health Policy:

[Medicaid Developmental Screening Policies by State](#) (Last Updated, May 2019)

Johns Hopkins Bloomberg School of Public Health:

[In Support of Family Caregivers: A Snapshot of Five States](#) (June 2019)

YOUR INPUT SOUGHT

Due August 12: [CMS Seeks Public Input on Patients over Paperwork Initiative to Further Reduce Administrative, Regulatory Burden to Lower Healthcare Costs](#)

(CMS Press Release, 6/6/19) This Request for Information solicits public comment on ideas for regulatory, subregulatory, policy, practice, and procedural changes that reduce unnecessary administrative burdens for clinicians, providers, **patients, and their families**.

Due August 13: Proposed Rule On Nondiscrimination In Health Care

In June, the Department of Health and Human Services (HHS) issued a [proposed rule](#) (Notice of Proposed Rulemaking) to revise regulations implementing Section 1557 of the Affordable Care Act (ACA) ([HHS Fact Sheet](#)). That ACA provision prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in any health program or activity that receives Federal financial assistance and certain other health programs or activities. Among the issues that the Notice of Proposed Rule Making seeks input on is, "whether HHS's Section 504 regulations at 45 CFR part 85 should be amended to address effective communication, accessibility standards for buildings of facilities, accessibility of electronic information technology, and the requirement to make reasonable modifications for otherwise qualified individuals with disabilities under any program or activity receiving Federal financial assistance from HHS." On July 1, the Kaiser Family Foundation issued a [summary and analysis of the proposed rule](#). Some analysts and advocates believe that, as written, the proposed rule would result in inadequate protections against discrimination for some of the protected populations. See [this article from the Health Affairs blog](#) (5/25/19); and [this article from the Commonwealth Fund](#) (6/12/19). Public comments on the proposed rule are due on August 13, 2019, and can be submitted [online via regulations.gov](https://www.regulations.gov).

Due August 19: Debt Collection Practices

The Consumer Financial Protection Bureau (CFPB) has issued a [Notice of Proposed Rulemaking](#) (proposed rule) to implement the Fair Debt Collection Practices Act (FDCPA). (See the CFPB [press release](#).) The proposal would protect consumers against harassment by debt collectors and provide them with options to address or dispute debts, including medical debt. See [Mired In Medical Debt? Federal Plan Would Update Overdue-Bill Collection Methods](#) (Kaiser Health News, 5/31/19). Comments may be submitted via [Regulations.gov](#) and are due no later than 11:59 pm ET, August 19, 2019.

FDA Patient Representatives

[See above, under “Other News...” for more information.]

Are you a patient or caregiver who wants to get involved at FDA? Contact [the Patient Affairs Staff \(PAS\)](#) or follow us on Twitter [@FDAPatientInfo](#). Should you wish to opt-out of future communications from the Patient Affairs Staff, please send an email to [PatientAffairs@fda.gov](#).

SPECIAL ANNOUNCEMENT

StoryBooth: Opportunity to Share YOUR Health Care Story!

Do you have a story about your health care experiences you’d like to share? Family Voices is working with the University of Pittsburgh to help promote their StoryBooth project. This is a research project designed to collect stories from patients and families about their experiences with health care. The hope is that by listening to the stories of people they can improve health care for others. In addition to stories from adults (patients and caregivers), they would like to include some stories from youth directly (must be at least 18 years old to participate). Stories are collected through phone interviews and then will be added to their [website](#). You can listen to some of the stories they’ve collected there. People who share their stories will be asked where they heard about the project, and then ask for permission to share the story with the source. Family Voices would love to be able to share your stories as well. Click on the links for two posters for general information and contact information:

- [General audience](#)
- [Youth audience](#)

OF POSSIBLE INTEREST

[Editor’s Corner -- I Write about Healthcare. I Still Found Myself Lost In The Unnavigable Healthcare System](#)

(Fierce Healthcare, 7/15/19)

[How a Small Provision of ACA Made a Big Difference for One Pennsylvania Family](#)

(Guest blog post, blog of the Georgetown Center for Children and Families, 7/9/19)

[Watch the Heart-Melting Moment When a Toddler Hugs a Stranger after Recognizing They Both Have Limb Differences](#)

WORTH REPEATING: [Family Burden and Medical Complexity: Wrestling with the Meaning and Impact of Commonly Used Terms](#), by Meg Comeau, MHA, Senior Project Director at the Center for Innovation

in Social Work & Health, Boston University School of Social Work, and parent of a young adult with a chronic condition. (The Lucile Packard Foundation for Children's Health, June 2019)

We at Family Voices would love to hear any suggestions you might have about how to make the Update more useful to you. Does it provide the right amount of information? What parts are helpful and not so helpful? Please let us know! Comments and questions can be directed to jguerney@familyvoices.org.

Yours truly,
Janis Guerney
Director of Public Policy
Family Voices

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