



Washington DC Update August 1, 2019

Greetings from Washington! GOOD NEWS! Congress has passed legislation to extend funding for Family-to-Family Health Information Centers (F2Fs) for five more years (through FY 2024) at the current funding level of \$6 million per year! The legislation also makes permanent the provision that requires the establishment of F2Fs for territories and tribes. Within the next few weeks, the president is expected to sign the bill into law. The F2F provisions are included in a bill that extends the Medicaid Money-Follows-the-Person Rebalancing Demonstration Program through December 31, 2019.* Also in this issue of the Update – news from the administration about helping pregnant women, mother and infants with substance abuse disorders; hospital-price transparency; drug importation; high-deductible plans; a new Lyme Disease test; and electronic visit verification.

***CORRECTION:** The 7/25/29 issue of the Update incorrectly reported that a bill to extend the Money-Follows-the-Person (MFP) program ([H.R. 259](#); Pub. Law 116-3) had been signed into law on *July* 24, 2019! Actually, that bill was signed into law on **January** 24, 2019, and extended the MFP program only through March 31, 2019! As noted above, the bill that extends F2F funding also extends the MFP program through the end of the year.

Meet with your Members of Congress during the August recess. Members of Congress will be back at home in August, and it's a good idea to make an appointment as soon as possible. You can find the local-office numbers for your Members of Congress at www.contactingcongress.org. And check <https://townhallproject.com/> to find town halls and other public events where you might be able to see your Representative or one of your Senators. Their time at home provides a great opportunity to educate them about the needs of children and youth with special health care needs (CYSHCN) and their families. You can also educate them about your state's Family-to-Family Health Information Center, and let them know how federal policies affect your children and family. To make your messages more memorable, go with other families and bring your children (or photos of them). If you want to brush up on how a bill becomes a law, check out [The Essential Guide to Legislation](#) (from Politico Pro).

REMINDER: 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.) **Deadline: 9/16/19]**

UPCOMING WEBINARS AND CALLS

Welcome to #ABLEtoSave Month: [Opening an ABL Account: Key Decisions for Success](#)

Thursday, August 8, 2:00-3:00 pm ET

Future webinars:

- August 15: ABL Best Practices and Action Steps for Family Members and Supporters(Circle of Support)
- August 22: ABL Best Practices for Working-Age Adults
- August 29: Celebrating All the Ways You are ABL: Announcing Winners from #ABLEtoSave Video Contest and Next Steps!

[Changes to the 2016 Federal Nursing Home Regulations: What's Proposed, What's Final, & What to Do About It](#)

Thursday, August 8, 4:00 pm ET

Justice in Aging

[Why Being Brain Injury Informed Is a Critical Component of Person-Centered Thinking, Planning, and Practice](#)

Monday, August 12, 3:00-4:30 pm ET

National Center on Advancing Person-Centered Practices and Systems (ACL and CMS)

[Critical Crossroads: Pediatric Mental Health Care in the Emergency Department](#)

Thursday, August 15, 3:00-3:30 ET

Health Resources and Services Administration

This webinar will discuss a new toolkit to help prepare hospital emergency departments to manage care for children and adolescents in mental health crisis.

[Person-Centered Planning and Practice](#)

National Quality Forum/Administration for Community Living; Centers for Medicare and Medicaid Services

- Friday, September 6, 2019, 1:00-3:30 pm ET
- Friday, December 13, 2019, 1:00-3:30 pm ET
- Monday, January 6, 2020, 1:00-3:30 pm ET
- Monday, February 3, 2020, 12:30-3:00 pm ET
- Monday, June 1, 2020, 1:00-3:30 pm ET

THE COURTS

[Federal Judge Strikes New Hampshire's Medicaid Work Requirements](#)

(The Hill, 7/29/19) A federal judge has vacated the administration's approval of a New Hampshire waiver request to establish work/community engagement requirements as a condition of Medicaid eligibility, and to eliminate three-month retroactive coverage! The basis for the decision was the agency's failure to take into account how many people would lose Medicaid coverage as a result of the waiver. The same judge also struck down the work-requirement waiver approvals for Kentucky and Arkansas!

CONGRESS

Congress Clears Bill to Extend F2F Program and Money-Follows-the-Person

The House and Senate have both passed a bill to fund **Family-to-Family Health Information Centers** (F2Fs) for five more years – through FY 2024 – at the current funding level of \$6 million per year! The legislation also makes permanent the provision that requires the establishment of F2Fs for territories and tribes! Within the next few weeks, the president is expected to sign the bill into law.

The F2F provision was included in a bill, the [*Sustaining Excellence in Medicaid Act of 2019*](#) (H.R. 3253), which was formerly titled the *Empowering Beneficiaries, Ensuring Access, and Strengthening Accountability Act of 2019*, sponsored by Rep. Deborah Dingell (D-MI). The bill also extends several other programs, including the **Money-Follows-the-Person** demonstration program and the **Certified Community Behavioral Health Clinic** demonstration program. The original bills to extend the F2F program (S. 1647 and H.R. 2822) were sponsored by Senators Chuck Grassley (R-IA) and Robert Menendez (D-NJ), and by Representatives Mikie Sherrill (D-NJ) and Fred Upton (R-MI). For more background information, see the [Family Voices website](#).

This 5-year funding extension will help F2Fs more effectively and efficiently plan ahead, retain experienced staff, and expand partnerships in the community.

House Passes Two-Year Budget Bill; Senate to Vote this Week

On July 25, the House passed a bill reflecting a budget agreement between House Speaker Nancy Pelosi and Treasury Secretary Steve Mnuchin! The legislation, which is [supported by the president](#), will increase both defense and non-defense “discretionary” (appropriated) spending for federal fiscal years 2020 and 2021, and suspend the nation’s debt ceiling until July 31, 2021, averting a default on the national debt until later that year! See [Sweeping Budget Deal Passes House Despite Weak GOP Support](#) (Politico, 7/25/19). A Senate vote is expected by the end of this week! See [As Republicans balk at nation's debt, Senate holds final vote on Trump-backed budget deal](#) (CBS News, 7/31/19).

EMSC Bill Passes Congress

On July 31, the Senate approved the House-passed bill ([H.R. 776](#)) to reauthorize the [Emergency Medical Services for Children \(EMSC\) program](#). The bill now goes to the president to be signed into law.

Bipartisan Bill to Lower Rx Drug Prices

On July 25, the Senate Finance Committee took up a bipartisan bill to address prescription drug prices! (See [details on the committee website](#).) The bipartisan bill was written by the Republican Chairman of the committee, Senator Chuck Grassley of Iowa, along with the committee’s Ranking Democrat, Senator Ron Wyden of Oregon. It was approved on a vote of 19-9, with support from only six of the committee’s 15 Republicans. The president supports the bill, while the pharmaceutical industry opposes it! See [Drug cost bill advances but GOP resistance spells trouble](#) (Associated Press, 7/25/19); [GOP Senators Distance Themselves From Grassley And Trump’s Efforts To Cut Drug Prices](#) (Kaiser Health News, 7/25/19). See also [Grassley: Goldilocks Moment to Reduce Rx Prices](#), Prepared Floor Remarks by U.S. Senator Chuck Grassley of Iowa, Wednesday, July 31, 2019. For more information, see the [July 25 Washington Update](#).

MEDICAID NEWS, INFORMATION, AND RESOURCES

[CMS Announces New Support for Babies, Pregnant Women, and Mothers Affected by Substance and Opioid Use Disorders](#)

(CMS Press Release, 7/29/19)

The Centers for Medicare & Medicaid Services (CMS) released two Informational Bulletins intended to help mothers and infants with substance abuse disorders -- [Caring Recovery for Infants and Babies](#) (CRIB) and [Help for Moms and Babies](#) (HMB). These Bulletins discuss certain provisions of the *Substance-Use Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities Act* (SUPPORT Act) that provide new coverage options to state Medicaid programs to provide care to infants, pregnant women, and mothers with Substance Use Disorder (SUD), including opioid use disorder (OUD).

WORTH REPEATING: [Understanding Medicaid Buy-in: A Tool to Advance Employment for People with Disabilities](#)

The Administration for Community Living, the Centers for Medicare & Medicaid Services (CMS), and the Department of Labor's Office of Disability Employment Policy (ODEP) have released a new "question and answer" document to help grantees, stakeholders, and self-advocates better understand the "Medicaid buy-in" program, through which states can allow workers with disabilities who are earning income to charge premiums for Medicaid coverage.

MEDICAID WAIVERS

[CMS Statement on Partial Medicaid Expansion Policy](#)

(CMS Press Release, 7/29/19)

The Centers for Medicare and Medicaid Services (CMS) announced that it will not approve state requests to expand Medicaid only partially, as opposed to expanding it to the full extent allowed under the Affordable Care Act (ACA). Accordingly, CMS denied Utah's waiver for a partial Medicaid expansion, which the state pursued in lieu of the full expansion approved in a voter referendum. See [‘We Probably Have To Implement The Thing’: Failure Of Utah Legislature’s Medicaid Plan Tees Up Full Expansion — Again](#) (Salt Lake Tribune, 7/29/19)

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

[Governors weigh health care plans as they await court ruling](#) (Associated Press, 7/25/19)

As reported in earlier Updates, a federal appeals court recently heard oral arguments in the case of *Texas v. United States*, in which a federal district court ruled that the entire Affordable Care Act is unconstitutional. At the National Governors Association conference last week, some of the nation's governors spoke about preparing for a ruling. See [The Latest Legal Challenge to the Affordable Care Act, Explained](#) (Vox, 7/10/19).

TRICARE

[Avoid Bug Bites on Vacation with These TRICARE Tips](#)

(TRICARE Benefits Update, 7/30/19) Tips in preparing for and traveling out of area or out of country.

[Sign up for TRICARE email updates.](#)

Connect with TRICARE on [Facebook](#) and [Twitter](#).

OTHER NEWS, INFORMATION, AND RESOURCES

Administration Proposes Price-Transparency Rules for Hospitals

On July 29, the Centers for Medicare and Medicaid Services (CMS) [announced](#) (press release) a [proposed rule](#) that would, among other things, require hospitals to make public their “standard charges” (gross charges and payer-specific negotiated charges) for all items and services, beginning in calendar year 2020! See [CMS Fact Sheet](#). Both the American Hospital Association and the America’s Health Insurance Plans (insurer trade group) have criticized the proposal, contending that disclosure of payer-specific prices will make it more difficult to negotiate discounts! See [Trump Administration Proposes First Rule On Health-Care Cost Transparency](#) (Washington Post, 7/29/19); [Trump administration wants to force hospitals to disclose secret negotiated prices](#) (The Hill, 7/29/19).

[HHS Announces New Action Plan to Lay Foundation for Safe Importation of Certain Prescription Drugs](#)

(HHS Press Release, 7/31/19)

The U.S. Department of Health and Human Services (HHS) announced that HHS and the Food and Drug Administration (FDA) are publishing a [Safe Importation Action Plan](#) outlining two potential pathways that would lay the foundation for the safe importation of certain drugs originally intended for foreign markets, such as Canada. See [Trump administration issues plan to allow imports of cheaper prescription drugs](#) (The Hill, 7/31/19).

[Treasury Recognizes Preventive Care for Chronic Conditions Under High Deductible Health Plans](#)

(The National Law Review, 7/31/19)

Pursuant to a June [Executive Order](#), the Treasury Department issued [guidance](#) listing particular preventive care items and services that may be covered by a high deductible health plan *before* the deductible has been met.

[FDA Clears New Indications for Existing Lyme Disease Tests That May Help Streamline Diagnoses](#) (FDA News Release, 7/29/19)

[Electronic Visit Verification: CMS Offers Guidance on "Good Faith Effort" Extensions for States](#)

(Administration for Community Living, 7/30/19)

“EVV is required for all Medicaid-funded personal care services by January 1, 2020, and for home health services by January 1, 2023, unless the state receives a CMS authorized “good faith effort (GFE)” exemption. The Centers for Medicare & Medicaid Services (CMS) recently released guidance for states to apply for this exemption, which provides up to one year of extra time to come into compliance with EVV if needed.” View the [GFE extension guidance and form](#) and [additional EVV information and](#)

[resources](#). See also [EVV Update: Deadline to Implement EVV for Personal Care Services Delayed until 2020](#) (Aug. 2018). CMS has responded to approximately 500 EVV related inquiries from states and stakeholders through their evv@cms.hhs.gov mailbox. That mailbox remains available for questions and comments.

RESOURCES:

From Federal Agencies:

Substance Abuse and Mental Health Services Administration (SAMHSA)

Resources on suicide prevalence and prevention in African American children:

- [National Network to Eliminate Disparities in Behavioral Health Virtual Roundtable](#)
- [Age-Related Racial Disparity in Suicide Rates Among US Youths](#)
- [Shining a light on Suicide Prevention Strategies](#)
- [Fathers who care](#)
- [SAMHSA's Center of Excellence for Infant and Early Childhood Mental Health Consultation \(IECMHC\)](#)
- [APA Health Disparities in Racial/Ethnic and Sexual Minority Boys and Men](#)

From Other Organizations:

National Conference of State Legislatures: The new [Health Innovations toolkit](#), which contains 12 briefs providing an overview of options policymakers might consider when examining health coverage in their states, including one [report on how Medicaid can help high-need, high-cost enrollees](#).

National Academy of Medicine: [Vibrant and Healthy Kids: Aligning Science, Practice, and Policy to Advance Health Equity](#), a new report outlining steps needed to move all children toward positive health paths, reducing health gaps.

Urban Institute: [Adults in Immigrant Families Report Avoiding Routine Activities Because of Immigration Concerns](#) that examines the "chilling effect" experienced by immigrant families from using public benefits.

WORTH REPEATING: National Alliance on Mental Illness (NAMI):

[Say It Out Loud: Speaking with Teens about Mental Health](#) gives adults tools to talk with teens about mental health, with the aim of removing stigma associated with getting treatment. It resource be adapted for use by community-based organizations, faith-based organizations and schools.

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](#).

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 [this page on Regulations.gov](#) and are due no later than 11:59 pm ET, August 19, 2019.

Due Sept. 13: Proposed Rescission of Rule on Equal Access to 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 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. Comments can be submitted through [this page on Regulations.gov](#).

Due September 23: Food Stamp Eligibility

The administration has issued a [proposed rule](#) that would restrict state flexibility to expand eligibility for food stamps. The Department of Agriculture estimates that the proposal would make 3.1 million people ineligible for the program. Comments may be submitted through September 23 via [this page on Regulations.gov](#). See also [Trump Proposal Would Push 3 Million Americans Off Food Stamps](#) (Washington Post, 7/23/19); [Trump Administration Moves to End Food Stamps for 3 Million People](#) (Bloomberg, 7/23/19).

FDA Patient Representatives

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](#).

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

[Autistic Perspectives Needed: Community Participation Services and Research Are at a Critical Juncture](#) (Health Affairs blog, 7/17/19)

[Pediatric Research: Implicit Race Bias Needs Critical Check in Health Care](#) (The Columbus Dispatch, 7/28/19)

[Hurry Up and Wait: Docs Say Insurers Increasingly Interfere](#) (The Washington Post, 7/29/19)

[Parents Talk About Social Needs Screening – Identify Trust as a Major Issue](#) (blog of the Georgetown Center for Children and Families, 7/24/19)

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,
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Director of Public Policy
Family Voices

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