



# FAMILY VOICES<sup>®</sup>

Washington DC Update  
July 11, 2019

## Greetings from Washington!

One big health care news story this week is that a federal appeals court heard oral arguments in Texas v. U.S., the case challenging the constitutionality of the Affordable Care Act. Another significant event: on July 11, a House subcommittee is expected to take up legislation to extend funding for Family-to-Family Health Information Centers (F2Fs), among other bills. Read about these and other developments in this week's Update.

## APPLY TO BE AN ACA COUNSELOR or NAVIGATOR, or to get Navigator Funds:

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), **AND** the Centers for Medicare and Medicaid Services (CMS) has issued the Notice of Funding Opportunity (NOFO) for the Federally-facilitated Exchange (FFE) Navigator Program. See the ACA Section below for details.

## UPCOMING WEBINARS AND CALLS

### [CMS National Training Program – Coverage to Care \(C2C\)](#)

Thursday, July 11, 1:00-2:30 pm ET

*Centers for Medicare and Medicaid Services (CMS)*

This webinar is about CMS' Coverage to Care (C2C) initiative, which provides tools and resources to help people educate others about health coverage, connecting to primary care, and the importance of preventive services.

### [How to Apply to Become a Counselor Designated Organization \(CDO\)](#)

Thursday, July 11, 2:00-3:00 pm ET

*The Centers for Medicare & Medicaid Services (CMS)*

**RSVP:** To facilitate a quicker registration process on the day of the event, please pre-register.

**For:** Organizations seeking to become a Certified Application Counselor Designated Organization (CDO) in Federally Facilitated Marketplace states. (Currently certified CDOs need not attend.) The application period to become a CDO began on **June 12** and ends on **September 16, 2019**. The CDO application link can be accessed [here](#). CDO Application technical assistance webinar recordings, user guides, and more can be found [here](#). **For additional questions contact** [CACQuestions@cms.hhs.gov](mailto:CACQuestions@cms.hhs.gov).

### [Building Family Leadership and Voice](#)

Friday, July 12, 2:00-3:30 pm ET

*Substance Abuse and Mental Health Services Administration (SAMHSA) TA Network*

## **Nothing About Us Without Us: Authentic Youth Engagement in Public Health**

**Tuesday, July 16, 12:00-1:00 pm ET**

*American Public Health Association, and the Office of Population Affairs and Office of Adolescent Health, Office of the Assistant Secretary for Health (OASH), U.S. Department of Health and Human Services (HHS)*

## **Understanding How TRICARE for Life Coverage Works**

**Thursday, July 18, 1:00-2:00 pm ET**

*TRICARE; Military OneSource*

## **Partnering with Schools on Behavioral Health Innovations: Medicaid, YES and Centering to the Needs of Young Consumers**

**Thursday, July 18, 2:00-3:00 pm ET**

*Community Catalyst*

## **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 (NCAPPS)*

## **THE ADMINISTRATION**

### **Conscience Rule Effective Date Moved to Nov. 22, 2019**

On May 21, 2019, HHS finalized its [conscience protection rule](#) ([HHS fact sheet on rule](#)) with an effective date of July 22, 2019. This final rule expands the right of health workers to refuse to participate in activities with which they have a religious or moral objection, and is facing multiple lawsuits alleging that it is discriminatory. In light of this litigation over the rule, HHS agreed to delay the rule's effective date by four months, until November 22, 2019.

## **THE COURTS**

### **Federal Appeals Court Hears Case Challenging the Affordable Care Act**

On July 9, a three-judge panel of the Federal Court of Appeals for the Fifth Circuit, sitting in New Orleans, heard oral arguments in the appeal of the [lower court's decision](#) in [Texas v. United States](#). See [Validity of Obama Health Care Law at Issue in Appeal Hearing](#) (AP, 7/9/19). The district court judge had agreed with Texas and the other plaintiffs that, when Congress lowered to zero the tax penalty for failing to have insurance, it undermined the constitutional basis of the Affordable Care Act (ACA) – Congress' taxing power. The district court determined that this made the *entire* ACA unconstitutional, including elements not related to the law's insurance-related provisions. Since the U.S. Department of Justice, which normally defends existing laws, decided to side with the plaintiffs *against* the law, the lower court allowed other states and the House of Representatives to join the case in defense of the ACA.

There are several paths the appeals court could take. It could affirm the lower court's decision, which would mean that the ACA's pre-existing condition protections, premium tax credits, Medicaid expansion, and all other provisions would be invalid. On the other hand, the appeals court could rule that only the tax penalty ("individual mandate") is unconstitutional, in which case there would be no practical effect of the decision, since Congress already has *effectively* repealed the individual mandate by setting the penalty at zero. (Congress lowered the penalty to zero, rather than actually *repealing* the entire "mandate" provision, because of the arcane rules governing the type of bill in which the amendment was included -- a "reconciliation" bill.) Alternatively, the appeals court could decide that the "mandate" is unconstitutional and, therefore, so are the pre-existing condition protections, since those protections arguably depend on many people purchasing insurance. Even if the pre-existing condition protections were ruled to be invalid, the premium tax credits, Medicaid expansion, and other ACA provisions would remain in place.

There is no deadline by which the appeals court must issue a decision, but observers believe it could come as early as fall 2019. It is likely that the case ultimately will end up in the Supreme Court, particularly if the appeals court rules that the entire ACA is unconstitutional. For more information, see [The Latest Legal Challenge to the Affordable Care Act, Explained](#) (Vox, 7/9/19); [Explaining Texas v. U.S.: A Guide to the 5th Circuit Appeal in the Case Challenging the ACA](#) (Issue brief, Kaiser Family Foundation, 7/3/19); [press release](#) (7/3/19). A recording of the oral argument (about 1 hour, 50 minutes) can be heard [here](#).

## CONGRESS

### **F2F and Other Health Bills to be Considered by House Subcommittee**

On Thursday, July 11, the House Energy and Commerce Committee's Health Subcommittee is scheduled to hold a "markup" to consider and vote on ten bills to reauthorize and/or extend funding for various health programs. According to the [committee announcement of the markup](#), it is expected that an "Amendment in the Nature of a Substitute" (AINS) will be offered during consideration of one of these bills (H.R. 2328, addressing community health centers). **That substitute amendment would include a provision to extend funding for Family-to-Family Health Information Centers (F2Fs) for four more years at level funding of \$6 million per year.** Often, such substitute amendments are negotiated ahead of time between the majority and minority committee leaders. Some of the other bills to be considered during this markup include the Autism Collaboration, Accountability, Research, Education and Support (Autism CARES) Act, the Lifespan Respite Care Act, the Emergency Medical Services for Children Program Reauthorization Act, the Newborn Screening Saves Lives Reauthorization Act, and bills to extend workforce development grant programs; nursing workforce development grant programs; the Community Health Center Fund; the National Health Service Corps; the Teaching Health Center Graduate Medical Education Program; the Special Diabetes Program; and the Special Diabetes Program for Indians. Also to be considered are bills to address surprise medical billing and prescription drug prices. Information for this markup, including the Committee Memorandum, electronic copies of the legislation and any amendments, and a link to the live webcast will be posted [on the committee website](#) when available. The markup is scheduled to begin at 10:00 am on July 11.

## **Senate Committee Approves Bipartisan Bill to Address Health Care Costs and Extend Funding for Public Health Programs**

On June 26, the Senate Committee on Health, Education, Labor & Pensions (HELP), reported out an amended version of a bill introduced by committee Chairman Lamar Alexander (R-TN) and Ranking Members Patty Murray (D-WA) – the *Lower Health Care Costs Act* ([S. 1895](#)). As noted in the [committee press release](#), the bill includes 54 proposals from 65 senators (36 Democrats and 29 Republicans). It addresses surprise medical billing, price transparency in insurance and health care, and prescription drug competition. The bill also provides five more years of funding, at the current level, for several public health programs – community health centers, the Teaching Health Center Program, and the National Health Service Corps.

## **MEDICAID NEWS, INFORMATION, AND RESOURCES**

### **[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.

### **[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.

### **[Leveraging Public Health Assets in Medicaid Managed Care](#)**

[This three-part report](#) from the Association of State and Territorial Health Officials (ASTHO) describes the current Medicaid and managed care context; the Medicaid managed care “life cycle”; and Medicaid managed care key obligations and goals and public health assets that can assist Medicaid in meeting these obligations.

## **WORTH REPEATING:**

- **[How Do Medicaid/CHIP Children with Special Health Care Needs Differ from Those with Private Insurance?](#)**  
(Kaiser Family Foundation Issue Brief, 6/12/19)

- [Medicaid’s Role for Children with Special Health Care Needs: A Look at Eligibility, Services, and Spending](#)  
(Kaiser Family Foundation Issue Brief, 6/12/19)

## MEDICAID WAIVERS

### Reminder:

- Approved and pending Medicaid waiver applications can be found on [Medicaid.gov](http://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:

- **Certified Application Counselor Designated Organizations - [Live Application Link now available](#).**

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](mailto:CACQuestions@cms.hhs.gov). **NOTE** the webinar for potential CDO applicants listed in the “Upcoming Webinars” section above.

- **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.

## TRICARE

From recent TRICARE Benefits Updates:

- [July 18 TRICARE Webinar on TRICARE For Life Coverage](#) (7/3/19)
- [Don't Guess. You have 24/7 Access to a Nurse](#) (6/27/19)
- [Moving? Update DEERS for Uninterrupted TRICARE Coverage](#) (6/24/19)

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## OTHER NEWS, INFORMATION, AND RESOURCES

### NEWS:

#### **[OIG: CMS Needs to Strengthen Hospice Oversight, Transparency](#)**

(Fierce Healthcare, 7/9/19)

The Office of the Inspector General (OIG) of the US Department of Health and Human Services issued a [report](#) finding that, between 2012 and 2016, 87 percent of hospices had at least one deficiency and 20 percent of hospices had serious deficiencies. See also [Hundreds of Hospice Centers in U.S. Get Failing Grades](#) (NBC, 7/9/19).

### RESOURCES:

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

##### **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.

##### **Food and Drug Administration (FDA):**

#### **New Video Series Featuring Testimonials from FDA Patient Representatives**

FDA Patient Representatives contribute to the agency's work regulating medical products—drugs, devices, and biologics. The agency has launched a series of videos, called "[When a Patient Speaks](#)," featuring testimonials from FDA Patient Representatives about what it means to serve in their unique role, the impact it's had on their lives, the lessons they've learned, and more. The [FDA Patient Representative Program](#)<sup>®</sup> is managed by the Advisory Committee Oversight and Management Staff within the Office of the Chief Scientist, Office of the Commissioner.

If you are a patient or caregiver who wants to get involved at the FDA, contact [the Patient Affairs Staff \(PAS\)](#) or follow [@FDAPatientInfo](#) on Twitter.

**Centers for Disease Control and Prevention (CDC):**  
[When Thunder Roars, Go Indoors! \(Español\)](#)

**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:**

**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**

**NEW - 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 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 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](mailto: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**

[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)

[With a surge in cases of mysterious polio-like condition, CDC appeals to doctors to help crack case](#) (STAT, 7/9/19)



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](mailto:jguerney@familyvoices.org).

Yours truly,  
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