



FAMILY VOICES[®]

Washington DC Update
December 19, 2019

BREAKING NEWS: A federal court of appeals has ruled on the case challenging the constitutionality of the Affordable Care Act (ACA), *Texas v. United States*. Key protections of the law remain in place pending further court action. See “ACA” section, below.

Greetings from Washington!

It has been a very busy few days in DC, not even considering the impeachment vote. Congress is getting ready to begin its between-session recess on December 20, and, as usual, the biggest deals get made just before such a deadline. Negotiators settled on details for funding all the agencies of the federal government through the remainder of the current fiscal year, and the president is expected to sign the legislation (two large bills). Also included in the deal are extensions of funding for Medicaid in the territories, community health centers, and other public health programs. **Not** included are measures to address surprise medical bills and prescription drug prices. Also this week, the administration announced a proposed rule intended to facilitate organ donation, and first steps toward allowing the importation of prescription drugs. Read about these issues, the ACA case, and more in this week’s Update.

UPCOMING WEBINARS AND CALLS

NEW [Building Effective Partnerships with Schools](#)

Friday, January 3, 2:00-3:30 pm ET

SAMHSA TA Network

SERIES [Person-Centered Planning and Practice](#)

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

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

NEW [State Systems and Resources for People Living With Traumatic Brain Injury](#)

Wednesday, January 15, 3:00-4:15 pm ET

ADvancing States

NEW Family Engagement and Leadership: Strengthening Systems, Services, and Communities

Thursday, January 23, 1:30-3:00 pm ET

SAMHSA TA Network

NEW Moving up the Ladder: Authentic Youth Engagement for Policy and Systems Change

Tuesday, January 28, 2:00-3:30 pm ET

SAMHSA TA Network

CONGRESS

END-OF-YEAR DEAL on APPROPRIATIONS AND MORE

House and Senate negotiators have reached a deal on spending for FY 2020, which began on October 1. See [Lawmakers Pile on the Spending In \\$1.4 Trillion Deal](#) (The Hill, 12/16/19), and the House has passed the measure. See [Massive Spending, Tax Packages Headed for Senate](#) (Roll Call, 12/17/19). The legislation will also extend some important health programs for five months, and includes some other significant policy provisions, as explained below.

Significantly, the deal does NOT include any provisions to address **surprise medical billing**. See [Surprising Swings In Momentum For Legislation On Surprise Medical Bills](#) (Kaiser Health News, 12/17/19). Nor does the deal include any major measures to control the cost of **prescription drugs**. [The Health 202: Congress Failed to Pass a Drug Pricing Overhaul. So It Set Another Deadline](#) (Washington Post "Power Post," 12/17/19).

Appropriations. Some programs of importance to children and youth with special health care needs (CYSHCN) and their families will receive increased funding this fiscal year. The deal will provide \$7.04 billion for the Health Resources and Services Administration (HRSA), a \$193 million increase over the FY 2019 level. Of that, there is an increase of \$17 million for the **Maternal and Child Health Bureau** (MCHB), which includes an increase of \$10 million for the **Title V MCH block grant**. The deal also includes an increase of \$5.25 million for the **National Center on Birth Defects and Developmental Disabilities** (NCBDDD) within the Centers for Disease Control and Prevention (CDC). Details about funding levels for programs within HRSA, the CDC, and other agencies of the Department of Health and Human Services (HHS) begin on page 15 of [this report](#). The report's section on special education (p. 136) also includes language regarding **Medicaid expenditures in schools**: "*Medicaid Services - Opportunities exist to streamline access to and improve the quality of special education services, and steps should be taken to reduce administrative barriers for providing health services in and in coordination with schools. The Office of Special Education and Rehabilitative Services should coordinate with the Centers for Medicare & Medicaid Services to develop training and provide technical assistance to assist with billing and payment administration for Medicaid services in schools.*"

"Health Extenders." A number of important health programs will be funded until May 22, 2020. These "health extenders" include: Community Health Centers; the Community Mental Health Services Demonstration program; the Money Follows the Person (MFP) demonstration program; Medicaid spousal impoverishment protections for home- and community-based services (HCBS); the Special

Diabetes Program; the Special Diabetes Program for Indians; the National Health Service Corps; and the Teaching Health Center Graduate Medical Education Program. While advocates are disappointed that these funding extensions are not longer, an advantage of the shorter extension is that it may be possible to get a permanent extension of some of the programs when their funding is reconsidered in May. Negotiators may have decided to provide only the short-term extensions in order to create pressure to enact legislation on surprise medical billing and prescription drug costs at that time. See [The Health 202: Congress Failed to Pass a Drug Pricing Overhaul. So It Set Another Deadline](#) (Washington Post “Power Post,” 12/17/19).

Medicaid in the Territories. The legislation will extend funding for the territories for two more years (through FY 2021, [two years less](#) than the committees of jurisdiction had approved) and increase the federal Medicaid matching rate from 55 to 70 percent in Puerto Rico and 55 to 83 percent in the other territories (the highest that any state gets).

PCORI. The deal includes a 10-year extension of the Patient-Centered Outcomes Research Trust Fund, which funds the Patient-Centered Outcomes Research Institute (PCORI), a government-sponsored non-profit that investigates the effectiveness of medical treatments to improve patient care. The legislation includes a provision for PCORI to better address issues faced by people with intellectual and development disabilities, and stops the use of the Medicare Trust Fund as a source for PCORI funding.

Other Significant Provisions.

- **Medical expense deductions:** The legislation includes a temporary 2-year extension of the 7.5% threshold for the medical expense deduction.
- **Tobacco:** The measure raises, from age 18 to 21, the federal age limit for selling tobacco products, including both cigarettes and e-cigarettes.
- **Minor Rx drug provisions:** The deal includes a provision requiring brand-name drug manufacturers to share drug samples with generic drug manufactures so that generics will be more readily available. It also includes provisions to help get lower-cost, biosimilar insulin to the market faster.
- **Gun violence research:** The bill includes \$25 million for the CDC and the National Institutes of Health to study gun violence, essentially reversing a rule in effect since 1996 that had prohibited the CDC from funding research that could be used to advocate for gun control. See [Congressional Deal Could Fund Gun Violence Research for First Time Since 1990s](#) (Washington Post, 12/16/19).

The legislation also includes some funding for a border wall, and [repeals three different taxes](#) established in the Affordable Care Act that had previously been delayed, including taxes on “Cadillac” health insurance policies and medical devices.

The president is expected to sign the bill by Friday, December 20, when the current temporary funding law (“continuing resolution”) expires.

MEDICAID/CHIP NEWS, INFORMATION, AND RESOURCES

MEDICAID WAIVERS

TENNESSEE -- WORTH REPEATING: Tennessee has submitted to CMS a waiver application to “block grant” its Medicaid program. They also request that they not be subject to Medicaid managed care regulations, including federal network adequacy standards. See [Tennessee Becomes New Front in Fight to Overhaul Medicaid](#) (The Hill, 12/01/19). Public comments on the Tennessee proposal are due on **December 27, 2019**.

- [Pending Application](#)
- [View/Submit Public Comments](#)

SOUTH CAROLINA WORK-REQUIREMENT WAIVER APPROVED: Last week, the Centers for Medicare and Medicaid Services (CMS) approved a community-engagement requirement for South Carolina, the first state in which the requirement (80 hours per month of work or volunteering) will apply to low-income parents. At the same time, the state will expand Medicaid eligibility to parents up to 100 percent of the federal poverty level for those meeting the work requirements. See [Trump Administration Approves Medicaid Work Requirements in South Carolina](#) (The Hill, 12/12/19).

KENTUCKY WORK-REQUIREMENT WAIVER RESCINDED: Newly elected Governor Beshear [officially rescinded](#) Kentucky’s 1115 waiver, including the state’s work requirement. See [Kentucky Gov. Beshear Rescinds Medicaid Work Requirements](#) (The Hill, 12/16/19).

ACA NEWS, INFORMATION, AND RESOURCES

BREAKING NEWS: A federal court of appeals has ruled on the case challenging the constitutionality of the Affordable Care Act (ACA), *Texas v. United States*. The appeals court (two judges of the 3-judge panel) affirmed part of the lower court’s ruling - that the ACA’s “individual mandate” is unconstitutional because the tax penalty to enforce it was repealed. But, the appeals court ordered the lower court to reconsider its ruling that the *entire* ACA is unconstitutional, that is, whether the rest of the ACA can be “severed” from the provision that created the tax penalty. Many health advocates are concerned about this ruling because the lower court is likely to maintain its position that the entire law is unconstitutional. If it does so, however, that ruling would again be subject to appeal.

It is possible that the appeals-court decision will be appealed immediately, either to the Supreme Court or to all the judges of the appeals court (an appeal to the court “en banc”). In any case, it will likely be many months until a final decision is rendered.

See [Federal Appeals Court Strikes Down Portion Of Obamacare](#) (Kaiser Health News, 12/18/19); for more detail, see [Appeals Court Strikes Down Individual Mandate in ACA Case, But Punts on Severability](#) (Fierce Healthcare, 12/18/19); and for even more detail, see [The Republican Judges Who Were Widely Expected to Kill Obamacare Got Cold Feet](#) (Vox, 12/18/19).

TRICARE

From TRICARE Benefits Updates: [How to Make Enrollment Changes Outside of TRICARE Open Season](#) (12/12/19)

For more information, please visit www.tricare.mil/OpenSeason or follow TRICARE on social media for regular updates:

- www.facebook.com/TRICARE
- www.twitter.com/TRICARE

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

OTHER NEWS, INFORMATION, AND RESOURCES

Organ Donation

On December 17, the administration announced a proposed rule intended to increase the number of organ donations. For more information, see the press release, [Organ Procurement Organization \(OPO\) Conditions for Coverage Proposed Rule: Revisions to Outcome Measures for OPOs](#), and [Trump Administration Announces Move Aimed to Increase Organ Donations](#) (The Hill, 12/17/19).

Importation of Prescription Drugs

[Trump Administration Takes Historic Steps to Lower U.S. Prescription Drug Prices](#)

Proposed rule could allow certain prescription drugs to be imported from Canada; draft guidance explains how manufacturers could import drugs, biological products originally intended for sale in another country (FDA News Release, 12/18/19). [Note: The proposed rule is not available online as of this writing.] See also [In a First Step, Trump Administration Unveils Two Proposals to Permit Drug Importation](#) (STAT News, 12/18/19).

YOUR INPUT SOUGHT

Tennessee Medicaid “Block Grant” Waiver – due December 27

Tennessee has submitted a waiver application to “block grant” its Medicaid program. CMS is accepting public comments. See [Tennessee Becomes New Front in Fight to Overhaul Medicaid](#) (The Hill, 12/01/19).

- [Pending Application](#)
- [View/Submit Public Comments](#)

[Nominations for Membership on the Interagency Autism Coordinating Committee \(IACC\) – due January 24, 2020.](#)

This [committee](#), which was reauthorized by the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019, is seeking nominations of individuals to serve as non-federal public members. The call for nominations is open through Friday, January 24, 2020. For more information on the IACC, see the [News Release](#) calling for nominations.

Proving Disability More Frequently – Due January 31, 2020

A proposed rule from the Social Security Administration, [Rules Regarding the Frequency and Notice of Continuing Disability Reviews](#) (Nov. 18, 2019), would require individuals receiving disability benefits to prove their disability more frequently. [Submit comments](#).

Input Sought from Family Caregivers – due February 7, 2020 (updated)

The Administration for Community Living (ACL) is seeking input on the challenges faced by family caregivers from individuals and organizations that capture the breadth of the family caregiving experience. This information will be used to assist the RAISE [Family Caregiving Advisory Council](#) in developing its initial report to Congress and to inform the development of the national family caregiving strategy. It also will be used to help the Council plan future activities, including public listening sessions that will begin in 2020. **To provide your input, please complete the [form](#) 11:59 p.m. EST on Friday, February 7, 2020.**

FDA Patient Representatives. Are you a patient or caregiver who wants to get involved at FDA? Contact [the Patient Affairs Staff \(PAS\)](#) or follow them on Twitter [@FDAPatientInfo](#).

From the Robert Wood Johnson Foundation: “That’s Medicaid”

Through its “[That’s Medicaid](#)” initiative, the Robert Wood Johnson Foundation is publicizing stories about how Medicaid has helped people in various situations. These stories might be helpful as you educate policymakers and the public about Medicaid. People can submit their own Medicaid stories [here](#) (scroll down).

OF POSSIBLE INTEREST

[American Academy of Pediatrics Report Provides Sweeping Review of Evidence Concerning Autism Spectrum Disorder](#) (12/16/2019)

[My Baby Needed Expensive Intensive Care, But My Insurer Was Taking a Long Weekend. How Can This Be?](#) (STAT News, 12/13/19)

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,
Janis Guerney
Director of Public Policy
Family Voices

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U40MC00149. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by, HRSA, HHS, or the U.S. Government.