



# FAMILY VOICES<sup>®</sup>

Washington DC Update  
January 8, 2020

## **Greetings from Washington, DC!**

There has been a period of relative calm in the healthcare policy world in the past week. One interesting bit of news – the Supreme Court is considering whether to review, on an expedited basis, an appeals-court ruling in the case challenging the constitutionality of the Affordable Care Act – [Texas v. Azar](#). (See “Courts” below.) Also, see the “Administration” section for an interview with Seema Verma, the influential administrator of the Centers for Medicare and Medicaid Services (CMS). Finally, please check “Your Input Sought,” since comment periods are open on a number of issues - organ donation, the frequency of disability reviews, and a federal plan to support family caregivers.

**Best wishes for a happy new year to all readers of the Washington Update!**

**Highlight:** On December 26, the Centers for Medicare & Medicaid Services (CMS) released an [Informational Bulletin](#) with the updated [2020 Supplemental Security Income \(SSI\) and Spousal Impoverishment Standards](#).

## **UPCOMING WEBINARS AND CALLS**

### [Delivering Mental Health Services Through A Cultural Lens: What Can We All Do?](#)

**Thursday, January 9, 6:00-7:00 pm ET**

*Pacific Southwest Mental Health Technology Transfer Center (MHTTC)*

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

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

*ADvancing States*

### [Money Follows the Person – Tribal Initiative, Part 1](#)

**Wednesday, January 22, 2:00-3:00 pm ET**

*Centers for Medicare and Medicaid Services (CMS)*

### [Family Engagement and Leadership: Strengthening Systems, Services, and Communities](#)

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

*SAMHSA TA Network*

### [Moving up the Ladder: Authentic Youth Engagement for Policy and Systems Change](#)

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

*SAMHSA TA Network*

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

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

- **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*
- *[past] Monday, January 6*

## **[Special Enrollment Periods \(ACA\)](#)**

**Thursday, February 6, 2:00 pm ET**

*[Health Reform: Beyond the Basics](#)/Center on Budget and Policy Priorities*

## **[Marketplace Appeals Process \(ACA\)](#)**

**Tuesday, February 25, 2:00 pm ET**

*[Health Reform: Beyond the Basics](#)/Center on Budget and Policy Priorities*

## **THE COURTS**

As reported in the [December 19 Update](#), a federal [court of appeals 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. See [Appeals Court Ruling Leaves Large Swaths of ACA in Judge's Crosshairs, Experts Say](#) (FierceHealthcare, 12/19/19); [Continued Uncertainty as Fifth Circuit Strikes Mandate, Remands on Rest Of ACA](#) (Health Affairs blog, 12/19/19); [Leading Children's Health and Medical Groups Respond to Appeals Court Decision to Overturn Affordable Care Act's Individual Mandate](#) (AAP press release, 12/19/19).

The attorneys-general of California and the other parties arguing in favor of maintaining the ACA (20 other states and the US House of Representatives) have [asked the Supreme Court to review the appeals court decision](#) on an expedited basis, without waiting for the district court's review, so that the Court can render a decision by the end of June. On January 6, the Supreme Court ordered the states challenging the ACA (led by Texas) and the Trump administration to respond by Friday, January 10, to the other side's request for an expedited review of the case. See [Supreme Court Orders Quick Response in Obamacare Challenge](#) (NBC News, 1/6/20).

The Supreme Court is not required to hear the appeal, but will do so if four of the nine justices vote to hear it. It takes *five* justices, however, to decide that the case should be reviewed on an expedited basis. Thus, the Court could take the case, but not hear arguments until October, rendering a decision months later. It is not clear when the Court will decide whether to take the case at all and/or whether to do so on an expedited timeline.

## THE ADMINISTRATION

### [One-On-One with Trump's Medicare and Medicaid Chief: Seema Verma](#)

[video and transcript]

(Kaiser Health News, 1/3/20)

## CONGRESS

### Hearing on “Legislation to Improve Americans’ Health Care Coverage and Outcomes”

On January 8, the House Energy & Commerce Committee is holding a [hearing](#) (live-streamed) on seven healthcare-related bills described in the [Chairman’s Memo](#) to committee members:

- [H.R. 1379](#), the “Ensuring Lasting Smiles Act”
- [H.R. 2271](#), the “Scarlett’s Sunshine on Sudden Unexpected Death Act”
- [H.R. 2468](#), the “School-Based Allergies and Asthma Management Program Act”
- [H.R. 2477](#), the “Beneficiary Enrollment Notification and Eligibility Simplification Act of 2019” or the “BENES Act of 2019”
- [H.R. 3935](#), the “Protecting Patients Transportation to Care Act”
- [H.R. 4801](#), the “Healthy Start Reauthorization Act of 2019”
- [H.R. 5534](#), the “Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act”

### Ending the Diagnostic Odyssey Act of 2019

On December 19, Senator Susan Collins (R-ME), along with Senators Doug Jones (D-AL), Martha McSally (R-AZ) and Robert Menendez (D-NJ), introduced the [Ending the Diagnostic Odyssey Act of 2019 \(S. 3116\)](#). A similar bipartisan bill ([H.R. 4144](#)) was introduced in the House in August. As explained in [Senator Collins’ press release](#), the legislation would allow states to conduct Whole Genome Sequencing (WGS) services for children on Medicaid with a disease suspected to have a genetic cause. States would receive an enhanced federal match of 75 percent for the testing costs for the first three years the service is provided.

### REFRESHER: End-of-the-Year Deal on Appropriations and More

Just before adjourning for the holidays, Congress passed appropriations bills to fund the government for the remainder of the current fiscal year. The president has signed the legislation. The legislation will also extend some important health programs for five months, and includes some other significant policy provisions, as explained briefly below and in more detail in the [December 19 Update](#).

Significantly, Congress did not pass any legislation to address **surprise medical billing**, or the cost of **prescription drugs**. See [2019 Was Supposed to Be the Year Washington Lowered Drug Prices. What Happened?](#) (STAT, 12/20/19).

**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. Among other program increases, more funding was provided for the **Maternal and Child Health Bureau (MCHB)**, including \$10 million more for the **Title V MCH block grant**, the **National Center on Birth Defects and Developmental Disabilities (NCBDDD)**, the **Lifespan Respite Care Program**, the **National Family**

**Caregiver Support Program.** 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 House report](#).

**“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. In May, these programs will likely get additional or even permanent extensions. The need for these extensions may help provide impetus for legislation on surprise medical billing and prescription drug costs.

**Medicaid in the Territories.** The legislation will extend funding for the territories for two more years (through FY 2021, [two years fewer](#) than the committees of jurisdiction had approved), and will 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.

## MEDICAID/CHIP NEWS, INFORMATION, AND RESOURCES

### MACPAC Releases 2019 Edition of MACStats: Medicaid and CHIP Data Book

From [MACPAC press release, 12/18/19](#): The Medicaid and CHIP Payment and Access Commission (MACPAC) released the 2019 edition of the [MACStats: Medicaid and CHIP Data Book](#), with updated data on national and state Medicaid and state Children’s Health Insurance Program (CHIP) enrollment, spending, benefits, and beneficiaries’ health, service use, and access to care. A notable trend in this year’s data book is [the decrease in national enrollment in Medicaid and CHIP](#) for the second year in a row. Although enrollment increased in some states, it declined in 34 states and the District of Columbia. Overall, there has been **a cumulative decrease in Medicaid and CHIP enrollment of 2.6 percent over the past two years.**

### Updated State Chartbook from the Catalyst Center

The Catalyst Center’s [State Data Chartbook](#) provides data on selected indicators of health coverage and health care financing for CYSHCN in every state plus DC and Puerto Rico.

### Just FYI: Medicaid History

View a [history \(timeline\) of the Medicaid program](#), prepared by the Center for Health Care Strategies, Inc. (and identified by the Catalyst Center in a recent newsletter).

## MEDICAID WAIVERS

- **Nebraska.** Nebraska has submitted to the Centers for Medicare and Medicaid Services (CMS) an application for a new, five-year demonstration that would include a series of wellness, personal responsibility, and work requirements for adults in the Medicaid “expansion” population. The state is also seeking to waive retroactive coverage for all non-exempt adult beneficiaries. The [federal comment period](#) closes on January 17, 2020.
- **Tennessee.** Numerous health organizations submitted comments to the Department of Health and Human Services (HHS) on the Tennessee proposal to “block grant” the Medicaid program. Comments were due on December 27.

**WORTH REPEATING: South Carolina Work-Requirement Waiver Approved.** 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).

## ACA NEWS, INFORMATION, AND RESOURCES

The open-enrollment period for plans sold on the federally facilitated exchanges (healthcare.gov) has ended, but some state marketplaces are still open:

- California: January 20, 2020
- Colorado: January 15, 2020
- District of Columbia: January 31, 2020
- Massachusetts: January 23, 2020
- New York: January 31, 2020

## TRICARE

From TRICARE Benefits Updates:

- [TRICARE Deductibles and Catastrophic Caps Reset Jan. 1](#) (12/30/19)
- [Before New Year's, Update DEERS](#) (12/23/19)

More TRICARE info can be found at

[www.facebook.com/TRICARE](http://www.facebook.com/TRICARE) and [www.twitter.com/TRICARE](http://www.twitter.com/TRICARE)

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

## OTHER NEWS, INFORMATION, AND RESOURCES

### Updated SSI Eligibility Limits

On December 26, the Centers for Medicare & Medicaid Services (CMS) released an [Informational Bulletin](#) with the updated [2020 Supplemental Security Income \(SSI\) and Spousal Impoverishment Standards](#).

## YOUR INPUT SOUGHT

### [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.**

### **Organ Donation Regulations – due February 21, 2020**

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). **The proposed regulation can be found, and comments can be submitted on [Regulations.gov](#).**

## **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**

[In the Driver’s Seat: Improving and Protecting Non-Emergency Medical Transportation](#) (Community Catalyst blog post, Aug. 21, 2019)

[‘What The Health?’: How Do Other Countries Pay For Health Care?](#) (Kaiser Health News, 1/2/20)

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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