



FAMILY VOICES[®]

Washington DC Update
January 16, 2020

Greetings from Washington, DC!

It has been fairly quiet in the health policy world this week, but there are a number of good webinars coming up and several opportunities for submitting public comments on significant proposed rules, nominations, and Medicaid waivers, as well as concerns and ideas about family caregiving. Please check out the “Medicaid Waivers” and the “Your Input Sought” sections below.

UPCOMING WEBINARS AND CALLS

NEW Incorporating Community Voices to Improve Complex Care

Tuesday, January 21, 1:00-2:30 pm ET

Center for Health Care Strategies/[Better Care Playbook](#)

NEW Partnering with Families to Provide Programs for People with Intellectual and Developmental Disabilities

Wednesday, January 22, 1:30-2:45 pm ET

National Center on Advancing Person-Centered Practices and Systems (an initiative from the Administration for Community Living and the Centers for Medicare & Medicaid Services)

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

NEW Promising Practices in Social Determinants of Health Capacity Building:

Just Wanna Live My Best Life – Shaping Medicaid HCBS to Fit the Individual Priorities of Self-Advocates

Thursday, January 23, 3:00-4:30 pm ET

Administration for Community Living and the Centers for Medicare and Medicaid

NEW Debunking the Three Biggest Myths about Disability Benefits and Work

Wednesday, January 22, 3:00-4:30 pm ET

Social Security's Ticket to Work Program

NEW Strategies to Increase Financial Fitness with an ABLÉ Account

Thursday, January 23, 2:00 pm ET

ABLE National Resource Center

NEW Social Determinants of Health: Technology and Workforce Approaches

Monday, January 27, 1:00-2:30 pm ET

The National Institute for Health Care Management (NIHCM) Foundation

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

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

SAMHSA TA Network

NEW Genuine Resilience is Closer (and Easier) Than You May Think

Wednesday, January 29, 2:00 pm ET

National Caregiver Alliance

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

NEW REACH for Transition: Developing Independence: Supported Decision-Making, Part 1: Helping Youth/Youth Adults Take Charge of Their Healthcare

Tuesday, February 25, 12:00-1:00 pm ET

SPAN Parent Advocacy Network

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 affirmed part of the lower court's ruling - that the ACA's "individual mandate" is unconstitutional because the tax penalty to enforce it was reduced to zero - but ordered the lower court to reconsider its ruling that the *entire* ACA is unconstitutional. As reported in the [January 8 Update](#), the attorneys-general of

California and the other parties supporting the ACA (20 other states and the US House of Representatives) [asked the Supreme Court to review the appeals-court decision](#) on an expedited basis. Those challenging the ACA responded, arguing against expedited appeal. See [Trump Administration Tells Supreme Court No Need to Rush an Obamacare Ruling](#) (Washington Post, 1/10/20). The Supreme Court has not yet made a decision on whether to hear the case on an expedited basis (or at all).

THE ADMINISTRATION

WORTH REPEATING: [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 held a [hearing](#) (video available) on seven healthcare-related bills, which are 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” (Would make non-emergency medical transportation a mandatory benefit in the Medicaid law; currently it is mandated only by regulation.)

[H.R. 4801](#), the “Healthy Start Reauthorization Act of 2019”

[H.R. 5534](#), the “Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act”

MEDICAID/CHIP NEWS, INFORMATION, AND RESOURCES

WORTH REPEATING: [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.***

WORTH REPEATING: [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.

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**.

Georgia. Georgia has submitted a new, five-year [Sec. 1115 demonstration proposal](#) to CMS that would create a new eligibility group restricted to individuals with incomes between 35 percent and 100 percent FPL who work at least 80 hours a month. Those with incomes above 50 percent FPL would also have to pay a monthly premium to maintain eligibility. The [federal comment period](#) is open until **February 7, 2020**.

Idaho. On January 3, 2020, Idaho requested a new 5-year [section 1115 demonstration](#) that would allow the state to receive federal financial participation for inpatient, residential, and other services provided to otherwise-eligible Medicaid beneficiaries while residing in **institutions for mental diseases (IMD)** for diagnoses of substance use disorder (SUD) and/or serious mental illness (SMI)/serious emotional disturbance (SED). Federal public [comments can be submitted](#) through **February 8, 2020**.

Utah. CMS [approved Utah’s full expansion](#) up to 138 percent FPL as well as a work search requirement (applying for 48 jobs); the state will receive enhanced federal matching funds. CMS did not approve the state’s enrollment cap for the adult expansion population and removed the previously approved enrollment cap on the partial expansion adults.

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. It may be a while before HHS issues its decision.

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:

- [What You Need to Know if You're New to TRICARE](#) (Jan. 8, 2020)
- [New Year, New You: Stay Healthy With TRICARE in 2020](#) (Jan. 10, 2020)

More TRICARE info can be found at

www.facebook.com/TRICARE and www.twitter.com/TRICARE

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

OTHER NEWS, INFORMATION, AND RESOURCES

From CMS: Funding for American Indian and Alaska Native 2020 Outreach and Enrollment Cooperative Agreements

On January 13, the Centers for Medicare & Medicaid Services (CMS) [announced](#) nine new grant awards, totaling about \$6 million, under the Helping Ensure Access for Little Ones, Toddlers, and Hopeful Youth by Keeping Insurance Delivery Stable Act of 2018 (HEALTHY KIDS Act) Outreach and Enrollment Cooperative Agreements funding opportunity. The grant awards will fund outreach and enrollment strategies aimed at educating **American Indian and Alaska Native Children families** about the availability of Medicaid and Children's Health Insurance Program (CHIP) and directly assisting families with the application and renewal process. For more information and a list of grantees, see the [InsureKidsNow website](#).

From the Department of Education: Restraint and Seclusion

About a year ago, Secretary of Education Betsy DeVos [announced](#) an initiative to examine the possible inappropriate use of restraint and seclusion in our nation's schools. As part of this initiative, the Department recently produced a YouTube webinar, [Students with Disabilities and the Use of Restraint and Seclusion in K-12 Public Schools](#), to provide technical assistance to support children with disabilities and those within school systems serving students.

From the Library of Congress: [Surprise Billing in Private Health Insurance: Overview and Federal Policy Considerations](#) (Congressional Research Service, 12/12/19)

From the Georgetown Center on Health Insurance Reforms: [New Resource for Consumer Advocates on Out-of-Network Payment Disputes in Balance Billing Legislation](#) (Georgetown Center on Health Insurance Reforms, 1/9/20)

WORTH REPEATING: 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](#).**

NEW DOT Seeks Input on Proposal to Make Airplane Lavatories More Accessible – due March 2, 2020

The U.S. Department of Transportation (DOT) seeks public comments on a new [proposed rule](#) to improve restroom access for passengers with disabilities on single-aisle aircraft with 125 or more seats. The rule is based on [negotiated rulemaking](#) undertaken by DOT's Advisory Committee on Accessible Air Transportation, which included aviation industry representatives, disability rights advocates, and other stakeholders. The proposed regulation addresses lavatory interiors, on-board wheelchairs, and training of flight attendants. **Comments are due by March 2, 2020, and can be submitted [here](#).**

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](#).

Submit stories about how Medicaid has helped you to “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

[U.S. Diabetes Patients Turn to 'Black Market' for Medications, Supplies](#) (Reuters, 12/25/19)

Just FYI: Medicaid History (Repeat)

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).

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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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.