



# FAMILY VOICES<sup>®</sup>

Washington DC Update  
October 17, 2019

## Greetings from Washington!

Congress returned from a two-week recess on October 15. It now must develop and pass appropriations to keep the government funded past November 21. Still under consideration is legislation to address surprise medical bills and prescription drug costs, although it is not clear whether consensus can be reached on those contentious issues. As reported last week, a decision could come any day in the case of *Texas v. United States*, about whether the Affordable Care Act is constitutional. Read about these issues and more in this week's Update, and check below for a number of new webinars.

- **Special note:** Last week, Family Voices held a webinar on *Leadership in Family and Professional Partnerships* (LFPP, formerly the National Center for Family-Professional Partnerships). The [webinar slides](#) are now available.
- **Warning:** The Social Security Administration has received reports of fraudulent phone calls from individuals impersonating Social Security employees, including Ticket to Work Help Line staff. The callers have masked their phone numbers as the Ticket to Work Help Line's phone number. If you receive this fraudulent call, you may hear a recorded message that states that your benefits will end or that your Social Security Number will be suspended. The call then prompts you to "press 1" to connect to a live person. **Do not press 1. Instead, hang up.** If you suspect you have received a scam call, you should report the details of the call to the Social Security Administration's Office of the Inspector General at 1-800-269-0271 or [online](#). **The Office of the Inspector General at the Social Security Administration, offers tips to protect yourself from scams. You can review these tips [here](#).**

## NOTE:

- **The 2020 Open Enrollment Period is November 1, 2019 to December 15, 2019.** See the [list of 2019 CMS Navigator grantees](#).
- [Get Ready: TRICARE Open Season, Federal Benefits Open Season Begins Nov. 11](#)
- **Medicare's Medical and Drug Open Enrollment Period is October 15 - December 7**  
To find 2020 health and drug plans, compare coverage options, or estimate Medicare costs, go to [www.Medicare.gov](http://www.Medicare.gov). Click [here](#) for Medicare Open Enrollment Period Outreach and Media Materials.

## UPCOMING WEBINARS AND CALLS

## **SERIES: [Health Reform: Beyond the Basics](#)**

Beyond the Basics past webinars and other resources can be found at <https://www.healthreformbeyondthebasics.org/>

- **Open Enrollment 07 - [Part VI: Plan Selection Strategies](#)**  
Thursday, October 17, 2:00 pm ET  
Series archive:
- **[Immigrant Eligibility for Health Coverage Programs](#)**  
Tuesday, October 22, 2:00 pm ET  
Center on Budget and Policy Priorities
- **[Working with Immigrants: What Consumer Enrollment Assistance Providers Need to Know Now](#)**  
Tuesday, October 29, 2:00 pm ET  
Center on Budget and Policy Priorities
- **[Best Practices When Assisting People with Disabilities Enroll in Health Coverage](#)**  
Thursday, October 31, 2:00 pm ET  
Center on Budget and Policy Priorities

## **[The Role of Expressive Arts in Pediatric Palliative Care](#)**

Thursday, October 17, 3:00-4:00 pm ET

Coalition for Compassionate Care of California, Pennsylvania's Pediatric Palliative Care Coalition, and Greater Illinois Pediatric Palliative Care Coalition

Complimentary for parents.

## **[NEW Newborn Screening for Fragile X Syndrome and Other Developmental Disabilities](#)**

Tuesday, October 22, 3:00-4:00 pm ET

Association of University Centers on Disability

## **[Addressing Health Disparities in the LGBTQ+ Community](#)**

Wednesday, October 23, 12:30-2:00 pm ET

The National Institute for Health Care Management (NIHCM) Foundation

## **[NEW Care Integration Best Practices: Care Coordination Approaches for Children with Moderate to Intensive Behavioral Health Challenges](#)**

Wednesday, October 23, 1:00 pm ET

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

## **[NEW Overcoming Message Resistance](#)** [provides instructions for joining the webinar]

Wednesday, October 23, at 1:00 pm ET

CDC's Emergency Partners Information Connection (EPIC)

## **[The Next Steps to Improving Home Health Care for Children with Medical Complexity](#)**

Wednesday, October 23, 1:30-2:30 pm ET

Lucile Packard Foundation for Children's Health

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[In addition to reading the suggested article -- [Home Health Care for Children with Medical Complexity: Workforce Gaps, Policy, And Future Directions](#) (Health Affairs, June 2019) -- see [Not Just Along For The Ride: Families Are The Engine That Drives Pediatric Home Health Care](#) (Health Affairs blog, 4/18/19).]

### **[Navigating Parental Consent: Whose Signature Do You Need, When Do You Need It & Tips on How to Get It](#)**

**Wednesday, October 23, 3:00-4:00 pm ET**

*Healthy Students, Promising Futures Learning Collaborative*

### **[NEW Prepare Now for TRICARE Open Season and Federal Benefits Open Season](#)**

**Thursday, October 24, 1:00-2:00 pm ET**

*TRICARE/Military OneSource*

**[Also see TRICARE event on Oct. 31, below]**

### **[Supporting Employment for Transition-Age Youth with Disabilities: How ABLE Accounts and SSA Work Incentives Can Help](#)**

**Thursday, October 24, 2:00-3:15 pm ET**

*ABLE National Resource Center*

### **[Cultural Competence: What it Means for Person-Centered Thinking, Planning, & Practice](#)**

**Tuesday, October 29, 3:00-4:30 pm ET**

*National Center on Advancing Person-Centered Practices and Systems*

### **[NEW Social Determinants of Health, Social Risk Factors, and Social Needs: Defining Interventions and Partnership Opportunities](#)**

**Wednesday, October 30, 3:00-4:00 ET**

*Health Care Transformation Task Force*

### **[NEW TRICARE SITREP](#)**

**Thursday, October 31, 3:15–4:15 ET [intro video and question posting at 3:00]**

*TRICARE*

The TRICARE SITREP is a live Q&A session hosted on the TRICARE Facebook page. Here's how it works:

- Go to [facebook/TRICARE](#) on Oct. 31.
- We'll post an introductory video at 3 p.m. announcing that we're about to begin.
- Ask your question as a comment to that introductory post.
- We'll answer your questions live during the event.
- Questions are answered in the order they're posted.

Remember to stay on topic so everyone's questions can be addressed. We'll answer questions specific to your scenario, but please don't share your health information since it's a public forum. This is your opportunity to ask questions about the TRICARE and FEDVIP open seasons.

If you have friends and family who may have questions about open season, please help us spread the word about the TRICARE Webinar (Oct. 24) and TRICARE SITREP (Oct. 31).

## **NEW Implementing Wraparound Mental Health Services in Rural Communities**

Friday, Nov. 1, 2:00-3:30 pm ET

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

## **NEW What Matters Most in Driving Cross-Sector Partnerships for Complex Populations,**

Tuesday, November 5, 3:00-4:00 pm ET

*The Better Care Playbook and the National Center for Complex Health and Social Needs*

## **NEW State Respite Legislation: Advancing Respite for Family Caregivers**

Tuesday, November 12, 3:00-4:00 pm ET

*ARCH Sustainability Learning Collaborative*

## **Expanding Access to School Behavioral Services via Telehealth**

Thursday, November 14, 2:00-3:00 pm ET

*Healthy Students, Promising Futures Learning Collaborative*

## **SERIES Person-Centered Planning and Practice**

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

- 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
- *[past] Friday, September 6, 2019*

## **THE COURTS - REPEATED**

At any moment, the US Court of Appeals for the 5<sup>th</sup> Circuit could announce its decision in *Texas v. the United States*, the case challenging the constitutionality of the Affordable Care Act (ACA). The district court had ruled in December 2018 that the entire ACA is unconstitutional. A three-judge panel of the appeals court heard arguments in July. Although the administration has argued that the law is unconstitutional, it reportedly will seek a “stay” (postponement) of the decision, pending appeal, should the court invalidate the law. See [Trump Administration Plans to Delay Any Changes if the ACA Loses in Court](#) (Washington Post, 10/6/19). Either party to the case law could ask for the court of appeals to re-hear the case “en banc” – before *all* the judges of the court – or could appeal the case directly to the Supreme Court.

Background. As reported in [earlier Updates](#), the state of Texas and 17 other states challenged the constitutionality of the Affordable Care Act (ACA) in *Texas v. United States*. The district court ruled that the entire law is unconstitutional because Congress lowered to zero the tax penalty for failing to have insurance, thus undermining the constitutional basis of the law – Congress’ taxing power. The 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. It would be very difficult to find an alternative to the ACA that could get through

the current Congress. See [The Health 202: Here Are All the Ways a Court Could Stymie Obamacare](#) (Washington Post Health 202 blog, 10/8/19).

## CONGRESS

### Appropriations

Congress returned from recess on October 15. Now they *must* address FY 2020 appropriations, because the “continuing resolution” enacted last month expires on November 21. See [Short-Term Funding Bill Keeps Government Open, Also Includes Sound Provision Reducing Federal and State Medicaid Drug Costs](#) (Georgetown Center for Children and Families blog post, 10/3/19).

### Prescription Drug Prices

As explained in earlier Updates, both chambers of Congress and the administration seem serious about addressing high prescription drug prices, but there are significant differences of opinion about how to do so. The House Democrat’s bill (Speaker Nancy Pelosi’s [D-CA] “Lower Drug Costs Now Act of 2019” - [H.R. 3](#) text; [summary](#)) would require the government to negotiate Medicare payments for 25 or more key drugs. Senator Majority Leader Mitch McConnell (R-KY) has said, however, that the Pelosi bill is “dead on arrival” in the Senate. A bipartisan (but still controversial) Senate Finance Committee bill ([S. 2543](#)) would basically tie drug prices to the rate of inflation. See [The Health 202: Impeachment Inquiry Lowers — But Doesn't Kill — Chance for Drug-Pricing Deal](#) (Washington Post “Power Post” blog, 10/14/19).

### Recent developments:

- The Congressional Budget Office (CBO) released a [preliminary cost estimate](#) of the House Democrats’ bill, estimating that the main part of the bill would save the federal government \$345 billion over a seven-year period, but that the loss of revenue to drug companies could hamper research and development, resulting in about eight to 15 fewer new drugs coming to market over that seven-year period (compared to about 300 new drugs over 10 years, as usual). See [CBO: Pelosi Bill to Lower Drug Prices Saves Medicare \\$345 Billion](#) (The Hill, 10/11/19); [The Good, the Bad, and the Unknown in the House Plan to Lower Drug Costs](#) (Vox, 10/14/19).
- Leaders of the House Progressive Caucus [announced](#) on October 15 that they would support the Pelosi bill, after negotiating some changes they were seeking.
- The [House Blue Dog Caucus](#) of moderate Democrats, have called for the House to take up other drug-pricing legislation that could have bipartisan support in both the House and Senate. See [Blue Dogs Call on Congress to Take Up Additional Bipartisan Drug Pricing Legislation](#) (The Well News, 10/8/19).
- The House Energy and Commerce, Education and Labor, and Ways and Means committees are expected to mark up the bill this week.
- House Majority Leader Steny Hoyer (D-MD) has said that the House could vote on prescription drug legislation by the end of this month. See [House May Vote on Prescription Drug Bill This Month](#) (Washington Examiner, 10/11/19).

### LATE BREAKING NEWS:

An [Amendment in the Nature of a Substitute](#) for H.R. 3 (the Pelosi bill) was released on Wednesday. It includes an amendment (pages 30-31), sought by disability advocates, that prohibits the use of

research that treats extending the life of a person with a disability as less valuable than extending life of someone without a disability. (See Section 1182 of the Social Security Act.) This language is based on language included in the creation of the Patient Centered Outcomes Research Institute (PCORI) and Medicare coverage decisions.

### **Surprise Medical Bills**

As reported in the [October 9](#) and [October 3](#) Washington Updates, there is keen interest in addressing the problem of surprise out-of-network medical bills. It is a controversial issue, however. While all proposals would take the burden of surprise bills off patients, key stakeholders prefer different approaches. Providers (hospitals, physicians, physician practice groups) prefer payments negotiated with insurance companies; insurers and employers prefer that payments be based on “benchmark” prices for the area. One key House committee chairperson has proposed that Congress require the administration to figure out a solution through a formal negotiated rulemaking process. It has been reported recently, however, that a Senate sponsor of a bipartisan bill predicts that surprise-billing legislation will pass Congress by the end of the year. See [Federal Surprise-Billing Legislation Will Likely Pass Congress by End of Year, U.S. Senator Says](#) (Becker’s Hospital CFO Report, 10/14/19).

#### **State legislation on surprise bills and prescription drug prices:**

Meanwhile, many states are addressing these issues. See:

- [State Legislative Action to Lower Pharmaceutical Costs](#) (National Academy on State Health Policy, 9/26/19)
- [States Lead on Surprise Medical Billing Protections, Congress Poised to Follow](#) (National Academy on State Health Policy, updated 10/4/19)

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

### **Improving Access to EPSDT Services – Recommendations for Federal and State Agencies**

The Government Accountability Office (GAO), which does reports for Congress, recently released a [report](#) about how the federal government could help to ensure that children get the services to which they are entitled under Medicaid’s Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit. The report provides six specific recommendations for the **Administrator of the Centers for Medicare and Medicaid Services (CMS)**. A recent blog post from the Georgetown Center for Children and Families explains the GAO’s findings and recommendations - [GAO to CMS: Set Goals, Measure Progress on EPSDT \(Do Better\)](#).

Also addressing ways to improve EPSDT implementation is a recent issue brief from Manatt Health - [Keeping Medicaid’s Promise: Strengthening Access to Services for Children with Special Healthcare Needs](#) (PDF). This report, which was developed in collaboration with families, and its [executive summary](#) (PDF), offer eight best-practice strategies that **state Medicaid agencies** can use to ensure that CYSHCN receive the EPSDT and other Medicaid services to which they are entitled.

Another blog post from the Georgetown Center for Children and Families discusses the role of Medicaid in schools: [Healthy Schools Campaign Webinar Looks at Importance of Medicaid to Student Success](#) (10/11/19).

## MEDICAID WAIVERS

### [Federal Judges Question Value of Medicaid Work Requirements](#) (McClatchy, 10/11/19)

A federal court of appeals heard arguments last week on a case challenging the administration's approval of waivers that would allow Kentucky and Arkansas to establish work requirements for Medicaid beneficiaries. The lower court had ruled in both cases that the decision by the Centers for Medicare and Medicaid Services (CMS) to approve these waiver proposals was "arbitrary and capricious" – thereby violating the Administrative Procedures Act (APA) - because the agency failed to consider the impact of the waivers on health care coverage for the Medicaid population ("...ensuring Medicaid coverage for the needy is a key objective of the Act, the Secretary's failure to consider the effects of the project on coverage alone renders his decision arbitrary and capricious..."). The Arkansas waiver would establish work requirements on adults eligible for Medicaid under the Affordable Care Act's optional expansion of the program. The Kentucky waiver would establish work requirements on both the expansion population and adults traditionally covered by Medicaid. See the Kaiser [Medicaid Waiver Tracker](#).

#### 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](#).

## ACA NEWS, INFORMATION, AND RESOURCES

**NOTE: The 2020 Open Enrollment Period is November 1, 2019 to December 15, 2019. [View a list of 2019 CMS Navigator grantees.](#)**

### Assister Readiness Resources

Modules for the first week of the 2020 Assister Readiness Webinar Series are now posted and ready to view! These modules cover topics relating to Helping Consumers Apply for Marketplace coverage. You can find the recordings and transcripts for the *Helping Consumers Apply* Assister Readiness Webinar Series modules here:

- **Preparing to Apply**
  - [Recording \(mp4\)](#) | [Transcript](#)
- **Creating and Submitting Applications**
  - [Recording \(mp4\)](#) | [Transcript](#)
- **Application Assistance Simulation**
  - [Recording \(mp4\)](#) | [Transcript](#)

As a reminder, The 2020 Assister Readiness Webinar Series is a supplement to the 2020 web-based Assister Certification Training. This series will be delivered in two weekly installments and will help get you ready to serve Marketplace consumers during the 2020 open enrollment period. Each installment will include three viewable, on-demand educational modules, **and** a corresponding LIVE webinar that will recap that week's topics and give you a chance to ask questions.

**This Live Webinar Recap for the Week One Modules will take place on Tuesday, October 22nd at 2pm Eastern Time. Please stay tuned for the webinar invitation!**

## TRICARE

### About TRICARE Open Season

[See also the “Webinars” section, above, regarding a webinar and Facebook event about open season.]

- **FROM TRICARE: WHAT IS TRICARE OPEN SEASON AND WHY DOES IT MATTER?**  
TRICARE Open Season is the annual period when you can enroll in or make changes to your TRICARE Prime, including U.S. Family Health Plan, or TRICARE Select plan for the next year. The Federal Benefits Open Season is for enrollment in a Federal Employees Dental and Vision Insurance Program (FEDVIP) dental and vision plan. If you’re currently enrolled in a FEDVIP dental or vision plan and you don’t want to make a change, your enrollment will continue in 2020. If you wish to make changes to your existing plan, you must do so during open season. Both the TRICARE and FEDVIP open seasons will run from Nov. 11 to Dec. 9. Enrollment choices made during this period will take effect on Jan. 1, 2020.
  - [Information about TRICARE’S OPEN SEASON](#) – Nov. 11- Dec. 9
  - [2019 TRICARE Open Season, Federal Benefits Open Season Starts Next Month](#) (10/10/19)
  - [Compare 2020 FEDVIP Plans and Costs, Prepare for Open Season](#) (10/3/19)
- **TRICARE Health Matters Newsletter Issue 3**  
Oct. 15, 2019  
The latest TRICARE East Region and TRICARE West Region newsletters, and the TRICARE Overseas Program (TOP) Health Matters Newsletter have information about Open Season. They can be downloaded at [www.tricare.mil/publications](http://www.tricare.mil/publications),

### From TRICARE Benefits Updates:

[TRICARE Website Expands to Include Military Hospital Sites](#)  
10/15/2019

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

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

## OTHER NEWS AND INFORMATION

### [Social Security Announces 1.6 Percent Benefit Increase for 2020](#)

(SSA Press Release, 10/1/19); [additional information](#).

### NEW RESOURCES FROM AGENCIES AND PARTNERS:

From the Substance Abuse and Mental Health Services Administration (SAMHSA):

- [SAMHSA Launches New Suicide Prevention Resources Page](#)



The Substance Abuse and Mental Health Services Administration (SAMHSA) has launched a new webpage that contains videos and other resources to help prevent suicide and offer support to those in crisis.

- [\*\*New Center of Excellence for Infant & Early Childhood Mental Health Consultation\*\*](#)  
With support from SAMHSA, The Georgetown University Center for Child and Human Development has launched a new Center of Excellence for Infant & Early Childhood Mental Health Consultation (IECMHC)! This national technical assistance center is dedicated to the advancement and impact of the field of IECMHC through training, technical assistance, and resource development.

#### **From the CDC:**

- [Children and Youth with Special Healthcare Needs in Emergencies](#) (also [in Spanish](#)) and
- [Emergency Kit Checklist for Families with Children and Youth with Special Healthcare Needs \(CYSHCN\)](#)
- [Protecting the Health of Children with ADHD](#)

#### **From Wright's Law:**

- [FAQs about Individualized Education Plans \(IEPs\)](#) (current issue of the [Special Ed Advocate](#) newsletter)
- [More information about IEPs](#)

#### **WORTH REPEATING: From the CDC --**

October is Health Literacy Month. The "[Share & Interact](#)" section of the [CDC Health Literacy website](#) offers multiple resources, including the [Health Literacy Month Handbook: The Event Planning Guide for Health Literacy Advocates](#).

### **YOUR INPUT SOUGHT**

**Due October 31. HHS/NIH, *All of Us* Research Program: [Request for Information \(RFI\) to Inform Tribal Collaborations](#).** The *All of Us* research program seeks input on Tribal Nation issues and concerns, including the importance of proper handling of AI/AN biospecimens in accordance with Tribal beliefs and traditions, challenges with handling data from self-identified AI/AN individuals, and educating the research community on avoidance of stigmatizing research.

#### **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](#).

### **OF POSSIBLE INTEREST**

[Taking the Cops out of Mental Health-Related 911 Rescues](#) (Kaiser Health News, 10/11/19)

["The Power of My Voice: Advocating for People with Intellectual and Developmental Disabilities in Tennessee"](#) – This video features the Tennessee Disability Coalition and the Tennessee Justice Center (from Community Catalyst).

### **SPECIAL ANNOUNCEMENT**

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## **Data from the Combined 2017-2018 National Survey of Children’s Health Are Now Available through the Data Resource Center for Child and Adolescent Health**

The Data Resource Center for Child and Adolescent Health (DRC), under a cooperative agreement with the Health Resources and Services Administration’s (HRSA) Maternal and Child Health Bureau (MCHB), is excited to announce the release of the **National Performance Measures (NPMs) and National Outcome Measures (NOMs) data findings** from the **Combined 2017-2018 National Survey of Children’s Health (NSCH)**. All data are available through the **interactive data query** on [childhealthdata.org](http://childhealthdata.org)! The combined 2017-2018 NSCH is the second multi-year data set since the [redesign of the NSCH in 2016](#) and includes data from 52,129 children ages 0-17 years.

For more information and resources on the NSCH, such as fast facts, guide to topics and questions, changes across years, survey methodology, survey instruments, and more, please visit the [DRC NSCH Overview page](#). There are also numerous resources available at [HRSA MCHB’s webpage on the NSCH](#), including the [NSCH Fact Sheet](#). Public use files for the previous NSCH are also available through the [U.S. Census Bureau’s NSCH page](#).

The remaining estimates of the combined 2017-2018 NSCH will be available through the interactive data query in November 2019, and downloadable data sets will be available in winter 2020. Single year 2018 NSCH estimates, downloadable data sets, and codebooks will be available through the DRC in spring 2020. If you have any questions, please contact CAHMI at [info@cahmi.org](mailto:info@cahmi.org). If you contact them and you are a Title V leader, please be sure to include this information.

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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