



FAMILY VOICES[®]

Washington DC Update
December 19, 2018

GREETINGS FROM WASHINGTON!

The big news this week is the ruling by a federal district court in Texas that the entire Affordable Care Act (ACA) is unconstitutional. Although the court did not specifically state that the law should remain in effect pending appeal, the Department of Health and Human Services (HHS) has stated that the law remains in effect. It is expected that the ruling will be appealed to the 5th Circuit Court of Appeals, and ultimately perhaps to the Supreme Court. Meanwhile, back in DC, Congress and the president have not reached a deal on spending bills for seven federal departments for the remainder of the fiscal year. The disagreement relates to whether Congress will appropriate funds for a wall between the United States and Mexico. Without an agreement, a partial government shut-down could occur as of midnight on Friday.

PLEASE NOTE: THE NEXT ISSUE OF WASHINGTON UPDATE WILL COME OUT DURING THE WEEK OF JANUARY 7. BEST WISHES FOR THE HOLIDAYS AND NEW YEAR!

2019 Family Voices Leadership Conference Call for Presentations!

We invite YOU to share YOUR EXPERTISE!

The 2019 Family Voices Leadership Conference will be held May 8-10, in Washington, D.C. The 2019 Family Voices Leadership Conference will bring together a diverse community of family and youth leaders, family members, professional partners, and other stakeholders from across the country. Together we will learn from each other, share resources and expertise, explore ways to improve supports to families, learn new strategies for managing nonprofits, and increase capacity for families to partner in systems change.

Please complete a [Call for Presentations Proposal](#).

Proposals are due by January 15, 2019.

Questions? [Contact Beth Dworetzky](#) .

Note for those affected by recent natural disasters:

The Centers for Medicare and Medicaid Services (CMS) provides flexibility to states and individuals affected by natural disasters, including special enrollment periods for people buying insurance on the health exchange. See [CMS Strengthens Federal Support to Alaska Residents Affected by Earthquake](#) and [CMS Acts to Help with Typhoon Yutu Emergency Response](#). CMS also has a [Toolkit for Disaster Preparedness and Response for State Medicaid Agencies](#).

Missed TRICARE Open Season? There's Still Time to Act (until the end of the year)!

WORTH REPEATING: HEALTH INFORMATION FOR FAMILIES:

Eating Uncooked Flour or Raw Eggs Can Make You Sick. Don't Taste or Eat Raw Dough!

It's not only the eggs, but the flour too, so don't play with homemade clay either.

CDC: [Say No to Raw Dough!](#) | | [¡No coma masa cruda!](#)

FDA: [Raw Dough's a Raw Deal and Could Make You Sick](#) | | [La masa cruda es peligrosa y podría enfermarte](#) (also available in other languages)

UPCOMING WEBINARS AND CALLS

Create Your Crisis Communication Plan

Wednesday, December 19, 1:00 pm ET

Emergency Partners Information Connection (EPIC) program of the CDC

Click <https://zoom.us/j/336888256> to join the webinar or telephone:

Dial (for higher quality, dial a number based on your current location):

US: +1 646 876 9923 or +1 669 900 6833

Webinar ID: 336 888 256

Kevin & Avonte's Law: New Tool to Combat Wandering in Vulnerable Populations

Thursday, December 20, 2:00 pm ET

Alzheimer's Foundation of America (AFA), Autism Speaks and the National Alliance for Caregiving (NAC)

Tips, Tricks, and Trends for Building Effective Partnerships through Hospital Community Benefit: Making the Most of the Next Hospital Community Health Needs Assessment (CHNA) Cycle

Friday, December 21: 2:00-3:00 pm ET

Community Catalyst

Who's on Your Team? Connecting Your Goals with Great People

Tuesday, January 15, 2019, 1:00-2:00 pm ET (closed captioned)

University of New Hampshire Institute on Disability

This webinar is intended for youth, young adults, and the people that believe in them, and is appropriate for students from eighth grade through college, with and without disabilities. By the end of the hour, students will develop an action plan to help them put together a team of supportive people.

THE COURTS

Court Finds That the ACA Is Unconstitutional, But the Law is Still in Effect

No doubt you have heard by now about the recent ruling in a case challenging the constitutionality of the Affordable Care Act (ACA), [Texas v. United States](#) (also known as [Texas v. Azar](#)). A federal district court in Texas held that the entire ACA is unconstitutional because the law is premised on the congressional taxing power, and the tax penalty for not having insurance was effectively repealed in 2017 (by reducing the tax penalty to zero). The taxing power was the basis of the 2012 Supreme Court

decision ([NFIB v. Sebelius](#)) to uphold the ACA. See [Texas Judge Strikes Down ACA as Unconstitutional, But Long Legal Path Remains](#) (FierceHealthcare, Friday, 12/14/18).

Since the court announced its decision on the eve of the last day of this year's federal open-enrollment season, HHS issued a statement the following day: "The district court decision in *Texas v. Azar* is still moving through the courts. The Marketplaces are still open for business, and we will continue with open enrollment. There will be no impact to enrollees' current coverage or their coverage in a 2019 plan." In a [December 17 statement](#), HHS again said the law is still in effect because the court did not issue an injunction to halt its implementation.

Legal scholars from both sides of the political spectrum seem to agree that the Texas court's ruling is not well-justified – particularly the holding that the *entire* law is unconstitutional, since much of the ACA is completely operational without the "individual mandate," including the Medicaid expansion, various Medicare provisions, and modifications to the Indian Health Service. See [Legal Experts Rip Judge's Rationale for Declaring Obamacare Law Invalid](#) (Washington Post, 12/15/18).

The plaintiffs in the Texas case are attorneys-general from 20 Republican-led states, led by the Texas attorney-general. The defendant is the United States, which normally defends an existing law, but the Trump administration actually agreed with the plaintiffs in part. The administration did not go so far as to argue that the *entire* law should be invalidated, however. Attorneys-general from a number of Democratic-led states (and DC) were granted the right to intervene as parties to the case, arguing that the entire law should be upheld. Those 17 attorneys-general filed a brief on December 17 asking the judge to clarify that the ACA will remain in effect until appeals are completed. They asked the judge to act on the request by December 21, and to take the legal steps necessary for them to file an appeal. See [Coalition of State AGs Challenge Ruling of Unconstitutional ACA](#) (Healthpayer Intelligence, 12/18/18).

The case will be appealed to the U.S. Court of Appeals for the 5th Circuit, and then may be further appealed to the Supreme Court, which would not be able to hear it until its term beginning in October 2019. See [Controversial Ruling on Health Care Law Could Face a Skeptical Supreme Court — If It Gets There](#) (Washington Post, 12/17/18).

Congress could amend the ACA in order to make the case moot; for example it could re-impose a tax penalty of any size. The current Congress will not have time to do so, and it is unclear what will happen in the future. [Congress Could Get Rid of ACA Lawsuit, But Won't](#) (Axios, 12/18/18).

See also [Court Decision to Invalidate the Affordable Care Act Would Affect Every American](#) (blog of the Commonwealth Fund, 12/17/18).

CONGRESS

Congress and the president have not yet reached an agreement on funding for construction of a wall between the U.S. and Mexico, which the president is seeking. If they do not come to an agreement by December 21, there will be a partial government "shut-down" affecting seven departments and related agencies. (In an unusual turn of events, the appropriations bill for the Departments of Labor, Health and Human Services, and Education has already been enacted.)

Meanwhile, lawmakers have been busy. In recent weeks one or both chambers have passed several bills related to maternal and child health care:

Now before the Senate:

The Improving Medicaid Programs and Opportunities for Eligible Beneficiaries Act ([H.R. 7217](#); [text](#)), also known as the **IMPROVE Act**, which incorporates several Medicaid bills that had been introduced earlier, most notably scaled-back versions of the **ACE Kids Act**, which would allow states to receive Medicaid reimbursement for “health homes” to better coordinate care for children with medically complex conditions, and the **EMPOWER Care Act**, which would extend for three months the Medicaid “Money Follows the Person” program to help people transition from institutional to community-based care. Proponents of this bill are hoping that the Senate will pass it before the 115th Congress adjourns this month.

Now before the House:

The **Emergency Medical Services for Children (EMSC) Program Reauthorization Act** ([S. 3482](#)), introduced by Senators Robert Casey (D-PA), Brian Schatz (D-HI), and Orrin Hatch (R-UT), was passed by “unanimous consent” in the Senate on December 11, and now will move to the House. A companion bill was introduced in the House but has not been taken up in committee. Although there is not enough time for the bill to be taken up in committee before the end of the congressional session, it is possible that it could still be passed by the House. The [EMSC program](#), administered by the Maternal and Child Health Bureau, provides grants to states and territories to improve their response to pediatric emergencies.

Ready for the President’s Signature:

Update: The Preventing Maternal Deaths Act of 2017 ([H.R. 1318](#)). Since the last Update, this bill was passed by the Senate, so is now ready for the president’s signature. The legislation would provide funding to states and tribes to establish and improve maternal mortality review committees to investigate cases of maternal death and develop recommendations to prevent them.

The Prematurity Research Expansion and Education for Mothers who deliver Infants Early (“PREEMIE”) Reauthorization Act of 2018 ([S. 3029](#)). This bill was sent to the White House on December 13. It will reauthorize for five years programs at the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) to collect data about and improve the treatment and outcomes of premature infants, to educate providers and the public about the risk factors for having a preterm baby, and to improve maternal health.

Signed by the President:

Updated: The Improving Access to Maternity Care Act ([H.R. 315](#)). On December 17, **the president signed this bill**, which was passed by the Senate on December 6, 2018, and the House January of 2017. The bill requires the Health Resources and Services Administration (HRSA) to identify and assign providers to areas that have a shortage of maternity care health professionals.

Farm Bill

Last week, both houses of Congress approved, by large margins, the “conference report” (House-Senate compromise legislation) on the “farm bill,” the Agriculture Improvement Act of 2018 ([H.R. 2](#)). The bill reauthorizes a number of agriculture programs and the Supplemental Nutrition Assistance Program (SNAP), commonly known as the food-stamp program. The conferees rejected significant cuts to SNAP that had been included in the House version of the bill. The bill now goes to the White House for the president’s signature. For more information, see the website of the [Food Research and Action Center](#).

Senator Alexander will not run for re-election in 2020

As [reported in STAT](#), Senator Lamar Alexander (R-TN) has announced that he will not seek re-election when his term expires in 2020. Senator Alexander chairs the Senate Health, Education, Labor, and Pensions (HELP) Committee, which has jurisdiction over many provisions in the Affordable Care Act, and numerous other public health and medical research (including NIH) programs (but not including Medicare, Medicaid, or Family-to-Family Health Information Centers).

MEDICAID AND CHIP NEWS, INFORMATION AND RESOURCES

[Proposed Changes to Medicaid Managed Care Rule Will Reduce Access to Providers](#)

(Blog of the Georgetown Center on Children and Families, 12/6/18) - short

[Inside the Trump Administration’s Proposed Medicaid Managed Care Rule](#)

(Health Affairs blog, 12/5/18) - long

[Transforming Care Delivery and Payment for Children with Medical Complexity](#)

(Health Affairs blog, guest post by Mark Wietecha, President and CEO of the Children’s Hospital Association, 12/6/18)

[CMS Posts New Medicaid and CHIP Application Processing Time Report](#)

(Blog of the Georgetown Center on Children and Families, 12/10/18)

MEDICAID WAIVERS

Florida - Shorter Retroactive Coverage

CMS has [approved](#) Florida’s request to waive the normal 90-day retroactive coverage period for Medicaid and instead provide coverage retroactively for only 30 days before Medicaid eligibility begins. The shorter period will apply to all adults 21 and older, except pregnant women, including those seeking long-term care services. The new policy will go into effect February 1 and remain in place until June 30 unless state lawmakers vote to extend it. See [Florida Gets Federal Approval to Trim Retroactive Eligibility for Medicaid](#) (Miami Herald, 12/3/18)

[Arkansas Moves to Simplify New Medicaid Work Requirement Program](#)

(CNN 12/12/18)

Medicaid beneficiaries will be able to report their community-engagement hours by phone instead of computer only, and the state will provide public education about how to report hours.

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Virginia: [Virginia's 1115 waiver proposal](#), which includes a work requirement, premiums, and other provisions, is **open for federal comment until January 6, 2019**. If the waiver is approved, beneficiaries will initially be required to work 20 hours per month, increasing to 80 hours per month after one year. Failure to comply with the requirements will result in suspension of Medicaid benefits. The state proposes including a number of exemptions and exceptions. The state will also require eligible beneficiaries with incomes 100 to 138 percent of the federal poverty level to pay monthly premiums. The premium amount will be based on a sliding income scale. Beneficiaries will make monthly premium payments of \$5 to \$10.

[Submit Comments](#) (click "Answer the Questionnaire")

AFFORDABLE CARE ACT

The annual open-enrollment season for the federal health insurance exchange (HealthCare.gov) ended on December 15. [Some state exchanges are still open](#) for enrollment, however – those in California, Colorado, Massachusetts, Minnesota, New York, Rhode Island, and Washington, DC.

Although final numbers are not yet in, the number of enrollments in the federal exchange this year is likely to be lower than in previous years. This could be due to the repeal of the penalty for not having insurance ("individual mandate"), because more people have employment-based insurance, because more people allowed their current plans to be automatically extended without visiting HealthCare.gov, or because some people purchased the non-ACA-compliant plans that can now be sold pursuant to recent regulatory changes. See [State Insurance Department Consumer Alerts on Short-Term Plans Come Up Short](#) (blog of the Georgetown Center on Health Insurance Reforms, 12/17/18). In addition, some people may have been discouraged from enrolling at the last minute due to the December 14 court ruling that the ACA is unconstitutional. (See "The Courts" section above.) See [Obamacare Signup Period Ends Amid New Uncertainty](#) (The Hill, 12/17/18).

TRICARE

[Expanded TRICARE Coverage for Ambulance Services](#)

(12/13/18)

[Missed TRICARE Open Season? There's Still Time to Act!](#)

Dec. 11, 2018

If you missed TRICARE Open Season, you still have time to enroll. For this year only, you can enroll in or change your TRICARE Prime or TRICARE Select plan through Dec. 31, 2018, for coverage starting on Jan. 1, 2019. You may also change your type of enrollment, like switching from individual to family coverage.

OTHER NEWS, INFORMATION, AND RESOURCES

NEWS

[Hundreds of Thousands Weigh in on Proposed Public Charge Rule](#)

(Blog of the Georgetown Center on Children and Families, 12/12/18)

[Five States Saw Uninsured Rates Rise for Kids under 6 – Critical Early Development Years at Risk](#)

(Blog of the Georgetown Center on Children and Families (12/13/18))

RESOURCES

[Supported Decision-Making and the ABLÉ Act, Achieving Better Life Experience](#)

The beneficiary of an Achieving Better Life Experience (ABLE) account is also the owner of the account. An archived webinar and associated materials from the [National Resource Center for Supported Decision-Making](#) addresses: Who will make decisions about savings goals and disbursements from ABLE accounts? Are there less restrictive options for account owners than guardianship and the removal of decision-making authority?

WORTH REPEATING: New CLAS Report and Toolkit

The HHS Office of Minority Health has developed a [framework report](#) and [toolkit](#) to guide health care organizations' efforts in evaluating their implementation of the National Culturally and Linguistically Appropriate Services (CLAS) Standards. The toolkit distills the elements of the framework and can help guide evaluations across four settings (ambulatory care, behavioral health, hospitals and public health).

YOUR INPUT SOUGHT

NEW: HHS Seeks Public Feedback on Modifying HIPAA Privacy Rules – Due Feb. 12

The Office of Civil Rights (OCR) of the Department of Health and Human Services (HHS) has published a Request for Information (RFI) asking the public for comments on how regulations implementing the Health Insurance Portability and Accountability Act (HIPAA) can be improved to “facilitate efficient care coordination and/or case management, and/or promote the transformation to value-based health care,” including rule changes that would encourage providers and other covered entities to share treatment information with parents, loved ones, and caregivers of adults facing health emergencies (with a particular focus on the opioid crisis). Comments are due no later than **February 12, 2019**. [Read the RFI and submit comments.](#)

Previously Reported:

Comments on New Standards for ACA Innovation Waivers (§1332 waivers) – due Dec. 24

On October 22, the Centers for Medicare & Medicaid Services (CMS) and the U.S. Department of the Treasury (collectively, the Departments) released new [guidance](#) ([press release](#); [fact sheet](#)) on waivers authorized by section 1332 of the Affordable Care Act (ACA), which was intended to let states design innovative ways to insure their residents. The newly termed “State Relief and Empowerment Waivers” will let states allow the sale of insurance policies that do not meet all of the ACA’s standards, using criteria that are more flexible than those established by the Obama administration. These alternative plans may provide less robust coverage than would be allowed under the previous guidance, and would not necessarily have to cover pre-existing conditions. The new standards became effective on October 22, but the **administration is [accepting comments](#) on them through December 24**. **See the article above and the [October 31 Update](#) for background materials.**

Comments to FDA about Sesame Allergies – due Dec. 31

The Food and Drug Administration (FDA) has issued a "[Request for Information](#)" requesting input from the public about whether it should require that sesame be listed as an ingredient on food labels to help protect those with sesame allergies. Comments can be submitted [here](#).

Comments to CMS about Proposed Rule on Medicaid/CHIP Managed Care – due Jan. 14, 2019

On November 8, the Centers for Medicare & Medicaid Services (CMS) issued a [Notice of Proposed Rule Making](#) (NPRM) (proposed rule) to amend the [2016 managed care final rule](#) issued by the Obama administration. As explained in a [CMS Fact Sheet](#), the new proposed rule would give states "more flexibility to set meaningful network adequacy standards using quantitative standards that can take into account new service delivery models like telehealth." States would also have the authority to define "specialists" "in the most appropriate way for their programs." Among other objectives, the proposed rule is intended to make it easier for states to transition new services and populations into managed care. See [Medicaid Managed Care Proposed Rule Would Give States More Flexibility](#) (National Academy for State Health Policy, 11/20/18). **Comments are due January 14, 2019**, and can be submitted through [Regulations.gov](#).

OF POSSIBLE INTEREST

[Talking Matters: A Loving Mother’s Commitment to Honor Her Daughter’s End-of-Life Wishes](#)

(The Conversation Project blog post by Family Voices consultant Cara Coleman, 12/11/18)

[‘We’re Fighting For Our Lives’: Patients Protest Sky-High Insulin Prices](#)

(Kaiser Health News, 12/12/18)

[Almost 5 Million Americans Got More Paid Family Leave This Year](#)

(Bloomberg, 12/6/18)

[These Children Can Neither Move Nor Speak. Clowns and Engineers Are Trying to Listen to Their Inner Worlds](#)

(STAT, 12/13/18)

RESOURCES FOR OPEN ENROLLMENT

Health insurance marketplaces are still open for enrollment in California, Colorado, Massachusetts, Minnesota, New York, Rhode Island, and Washington, DC. The following resources might be helpful to consumers.

[Health Insurance Marketplace Calculator](#)

This tool from the Kaiser Family Foundation provides estimates of health insurance premiums and subsidies for people purchasing insurance on their own in health insurance exchanges (or "Marketplaces") created by the Affordable Care Act (ACA). With this calculator, you can enter your

income, age, and family size to estimate your eligibility for subsidies and how much you could spend on health insurance. You can also use this tool to estimate your eligibility for Medicaid.

[Health Plan Comparison Worksheet](#)

A worksheet created by Cover Missouri to adequately compare health plans available on and off of the ACA marketplace.

[Navigator Resource Guide](#)

The Georgetown Center on Health Insurance Reform (CHIR) has updated this guide, which provides answers to 300 frequently asked questions (FAQs) about ACA requirements and health insurance, and commonly asked questions for small businesses and individuals with employer-based coverage. The Guide includes a "[What's New in 2019](#)" section, which includes information about the new policies for marketplace coverage in 2019 that will affect this year's open enrollment. Additional publications by CHIR researchers can be found [here](#).

[Short-Term Plans Resource](#)

This is a palm card designed by the Colorado Consumer Health Initiative to inform consumers about the pitfalls of short-term limited duration health plans.

[Buying Children's Dental Coverage through the Marketplace](#)

(Families USA and Children's Dental Health Project)

More:

- [As Open Enrollment Begins, Good Reasons to Visit Insurance Marketplaces](#) (Center on Budget and Policy Priorities)
- [Why Do Short-Term Health Insurance Plans Have Lower Premiums Than Plans That Comply with the ACA?](#) (Kaiser Health News, 10/31/18)
- [6 Common Open Enrollment Mistakes and How to Avoid Them](#) (TIME, 10/29/18)
- [What to Watch Out for During Open Enrollment](#) (CNBC, 10/27/18)
- [The Ins and Outs of High-Deductible Health Care Plans](#) (Minn. Public Radio, 49-minute audio story, 10/29/18)

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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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