



FAMILY VOICES[®]

Washington DC Update
October 9, 2019

Greetings from Washington!

Congress is still in recess, and will return on October 15. Outstanding issues to tackle when they get back include appropriations to keep the government funded past November 21, and legislation to address surprise medical bills and prescription drug costs. It is not clear whether a consensus can be reached on those contentious issues. On the judicial front, the US Circuit Court of Appeals for the 5th Circuit is expected to issue its decision soon in *Texas v. United States*, about whether the Affordable Care Act is constitutional. In other news, the Title V NOM/NPM data from the Combined 2017-2018 National Survey of Children's Health are now available at www.childhealthdata.org! (See "Special Announcements," below.)

IT'S RECESS! Members of Congress are home on a recess through October 14, which provides an opportunity for you to see them in their local offices or at town halls or other public events. It's a great chance to educate them about CYSHCN and their families, and about your Family-to-Family Health Information Center. To get contact information for your Members of Congress, see www.contactingcongress.org, or www.senate.gov and www.house.gov. For a list of public events in your area, [see the Town Hall Project](#).

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](#)

UPCOMING WEBINARS AND CALLS

NEW Bilingual Twitter Chat for Hispanic Heritage Month - #HealthyLatinos **Wednesday, October 9, 2:00 pm ET** [English](#) | [Spanish](#)

HHS Office of Minority Health (OMH) and the Office of Disease Prevention and Health Promotion (ODPHP)

In observance of [Hispanic Heritage Month](#), the chat will focus on health disparities and perceived barriers to health outcomes among the Hispanic/Latino community, how to maintain an active and healthy lifestyle and sharing bilingual resources. To participate, use hashtag **#HealthyLatinos**.

SERIES: Health Reform: Beyond the Basics

- [Part IV: Preventing & Resolving Data Matching Issues](#)
Thursday, October 10, 2:00 pm ET
- [Part V: Plan Design](#)
Tuesday, October 15, 2:00 pm ET
- [Part VI: Plan Selection Strategies](#)
Thursday, October 17, 2:00 pm ET

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

Series archive:

[Part I: Determining Households & Income for PTC & Medicaid](#)

Tuesday, October 1, 2:00 pm ET

[Part II: Premium Tax Credits](#)

Thursday, October 3, 2:00 pm ET

[Part III: Auto-Renewal Process for 2020 on Healthcare.gov](#)

Tuesday, October 8, 2:00 pm ET

NEW The Leadership in Family and Professional Partnerships Program: What It Is and How You Can Benefit!

Thursday, October 10, 3:00-4:15 pm ET

Family Voices Leadership in Family and Professional Partnerships (LFPP)

LFPP works to increase engagement of families of CYSHCN at all levels of health care through the provision of assistance, training, and resources to Family-to-Family Health Information Centers, Title V programs, and other CYSHCN stakeholders.

NEW Addressing Disparities in Health Care for Individuals with Intellectual Disabilities

Tuesday, October 15, 1:00 pm ET

Centers for Disease Control and Prevention (CDC), Public Health Grand Rounds

Get Ready for Seasonal and Pandemic Flu: Strategies for Early Care and Education Providers

Tuesday, October 15, 2:00-3:30 pm ET

National Center on Early Childhood Health and Wellness

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.

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

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

[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).]

NEW 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 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

NEW 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 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

At any moment, the US Court of Appeals for the 5th 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

Congress is in recess until October 15. When they return, 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). There is still continued interest in addressing prescription drug prices and surprise medical billing. Those are both controversial issues, however, so it may be difficult to craft legislation that can get through Congress. More information about these issues can be found in the [October 3 Update](#).

With respect to **surprise medical bills**, the chairman of the House Ways and Means Committee, Richard Neal (D-MA), has [suggested](#) that Congress enact a law requiring the administration to undertake a “negotiated rulemaking process.” Under such a plan, the administration would convene a committee consisting of key stakeholders (doctors, hospitals, insurers) and the Departments of Health and Human Services, Treasury, and Labor. That committee would recommend parameters for setting payment rates for surprise bills, while ensuring that consumers would be held harmless. The federal departments would then develop a proposed rule with a public comment period. The key stakeholders have different positions on how to pay these out-of-network payments. Physicians, physician practice groups, and hospitals prefer negotiated rates, while insurers prefer a “benchmark” approach. A good explanation of the issue can be found in [The Health 202: Doctors Are Gaining the Edge in Fight over Surprise Medical Billing](#) (Washington Post, 9/23/19). See also [We Need Benchmarking, Not Arbitration, to Quell Surprise Medical Billing](#) (STAT’s ‘First Opinion’ blog post, 10/7/19).

With respect to **prescription drug prices**, it has been reported that staffers from the administration and House Speaker Nancy Pelosi have been discussing her bill on the topic. See [Trump and Pelosi Aides Talk Drug Costs Despite Impeachment](#) (Associated Press, 10/1/19).

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

NEW Eight Steps to Ensure that CYSHCN Receive All Services Mandated under Medicaid

A new issue brief from Manatt Health [Keeping Medicaid's Promise: Strengthening Access to Services for Children with Special Healthcare Needs](#) (PDF), 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 services to which they are entitled under EPSDT and other benefits.

MEDICAID WAIVERS

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.](#)

RESOURCE: [The Health Care Assister's Guide to Tax Rules](#) (Updated Oct. 2019)

WORTH REPEATING: Community Outreach Collaboratives

The National Disability Navigator Resource Collaborative (NDNRC) has funded eighteen [Community Outreach Collaboratives](#) (COCs) for the upcoming open-enrollment season – expanding on the eleven COCs that were funded in year two. The COCs have two primary tasks: 1) build cross-disability collaborations with other disability organizations; and 2) have the cross-disability collaboration work as a dissemination and outreach resource with their local and/or state navigators and assisters. The 18 COCs are (by HHS regions) are available at <https://nationaldisabilitynavigator.org/about/community-outreach-collaboratives/>.

WORTH REPEATING: [CMS is Bringing Health Plan Quality Ratings to All Exchanges for the First Time](#)

(CMS News Release, 8/15/19):

For the first time, the Centers for Medicare & Medicaid Services (CMS) will require the display of the five-star Quality Rating System (or star ratings) available nationwide for health plans offered on the Health Insurance Marketplaces beginning with the 2020 Open Enrollment Period. Beginning with this year's Open Enrollment Period, consumers will be able to compare health coverage choices using a five-star quality rating of each plan on Marketplace websites, including [HealthCare.gov](#), similar to other CMS star rating programs, such as the Nursing Home Compare website. For more information, see the [fact sheet](#) available.

TRICARE

From TRICARE Benefits Updates:

- [Information about TRICARE'S OPEN SEASON](#) – Nov. 11- Dec. 9
- [Compare 2020 FEDVIP Plans and Costs, Prepare for Open Season](#) (10/3/19)

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

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

OTHER NEWS AND INFORMATION & RESOURCES

Applicants for Immigrant Visas Must Demonstrate Plan for Getting Insurance Coverage or Ability to Pay Medical Expenses

On October 4, President Trump signed a proclamation -- [Presidential Proclamation on the Suspension of Entry of Immigrants Who Will Financially Burden the United States Healthcare System](#). The proclamation announces that the government will accept immigrant visa petitions made abroad only if the applicant can demonstrate that he/she will be able to secure health insurance within 30 days of arriving in the US, or has the financial resources to pay "reasonably foreseeable medical costs." The requirement does not apply to tourists or certain other individuals, including: children of US citizens; other children under the age of 18 unless, they are accompanying a parent who is also immigrating to the United States and is subject to the requirement; asylees; or refugees. The proclamation also lists the types of insurance coverage that meet the requirement. Among others, short-term plans will be acceptable, as will Medicaid coverage for children through age 18. The requirement goes into effect November 3. See [Trump Order Requires Legal Immigrants Get Health Care Coverage Before Entry Into US](#) (USA Today, 10/5/19).

[Trump Administration Empowers Nursing Home Patients, Residents, Families, and Caregivers by Enhancing Transparency about Abuse and Neglect](#)

(CMS Press Release, 10/7/19) ([En Español](#))

Later this month, the Centers for Medicare & Medicaid Services (CMS) will be adding a new feature to the [Nursing Home Compare website](#). It will display a consumer alert icon next to nursing homes that have been cited for incidents of abuse, neglect, or exploitation. This website already provides information about whether a facility meets federal standards with respect to health and safety compliance inspections, staffing levels, and quality measure performance. The new format and icon will make it easier to quickly identify nursing homes with past citations for abuse.

NEW RESOURCES FROM AGENCIES AND PARTNERS:

From the FDA:

- [Epinephrine Treatments for Allergic Reactions: How to Prepare for Back-to-School](#) (FDA, 8/30/19)
- [FDA Updates and Press Announcements on NDMA in Zantac \(ranitidine\)](#) (most recent is from 10/2/19)

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](#).

From the Social Security Administration:

[Social Security Services for the Hispanic Community](#) (Social Security Matters blog post, 10/3/19)

From the Family Support Research and Training Center, University of Illinois at Chicago (September 2019):

[Research Brief: Social Support and Family Resilience Ease the Stress of Parents of Children with Complex Special Health Care Needs](#)

This research brief examined the effects three social determinants - community conditions, emotional support, and family resilience - on the physical and mental health of mothers of children with complex health care.

WORTH REPEATING:

From SAMHSA and CMS:

New Updates from C2C's Roadmap to Behavioral Health (useful for families)

The Centers for Medicare & Medicaid Services Office of Minority Health (CMS OMH), in partnership with Substance Abuse and Mental Health Services Administration (SAMHSA), has updated [The Roadmap to Behavioral Health](#). This *From Coverage to Care* (C2C) guide offers important information about mental health and substance use disorder services, finding a behavioral health provider, defining behavioral health terms, receiving services, and following up on care. It also includes links to other HHS services. To learn more or download C2C resources, visit cms.gov/c2c or email CoverageToCare@cms.hhs.gov.

- To receive updates on *From Coverage to Care*? Subscribe to the [C2C listserv](#).
- Order printed copies of this publication from the [CMS Product Ordering Website](#).

From the Catalyst Center:

[State-by-State Resources for Families](#)

This directory, organized by state, provides links to a wide range of direct service organizations, and to important information related to Title V Maternal and Child Health programs. Title V programs work to improve the health and well-being of women and children, including children with special health care needs.

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

- [Opioid Treatment Scam May Be Coming to Your State](#) (Stateline, 10/7/19)
- WORTH REPEATING: [The 7 Things Families Care About Most](#): One hospital was surprised to learn that parents don't cite patient safety as being important, and there's a theory why. (Children's Hospital Association, 9/9/19)

SPECIAL ANNOUNCEMENTS

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! 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. If you contact them and you are a Title V leader, please be sure to include this information.

Special Enrollment Period Available for Victims of 2019 Hurricane Dorian

Consumers who qualified for an another enrollment period, such as a special enrollment period (SEP) or Open Enrollment Period (OEP), but were unable to complete a Marketplace application, plan selection, or enrollment process due to Hurricane Dorian, may have access to an Exceptional Circumstances Special Enrollment Period (SEP). These individuals have 60 days from the end of the FEMA-designated incident period to complete their 2019 enrollment and request a retroactive start date based on when he or she would have picked a plan if not for Hurricane Dorian. Consumers will be considered “impacted” and eligible for this SEP if they reside, or resided at the time of the hurricane, in any of the [counties declared](#) as meeting the level of “individual assistance” or “public assistance” by the Federal Emergency Management Agency (FEMA). See [2018 guidance](#) on Special Enrollment Period (SEP) policy for consumers impacted by an emergency or major disaster. **Assisters, agents, and brokers can help affected consumers by contacting the Marketplace Call Center at 1-800-318-2596 or TTY at 1-855-889-4325 to request enrollment using this SEP.**

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

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