



FAMILY VOICES[®]

Washington DC Update
November 20, 2019

Greetings from Washington!

Congress is still working away on FY 2020 appropriations, and legislation to address surprise medical billing and prescription drug prices. Meanwhile, the Centers for Medicare and Medicaid Services (CMS) has been very busy. The agency released a significant proposed regulation on healthcare price transparency, and a proposed rule about ways that states can raise their Medicaid funds to match federal payments. In addition, CMS has released several Medicaid informational bulletins, including one about third-party liability responsibilities and one about the Medicaid managed care contract approval process. The Social Security Administration has released a proposed rule regarding continued disability reviews for SSI and other disability programs. (See “Other News,” below.) Read about these topics and more in this week’s Update, and check out the many new webinars listed below, including two taking place today on *parent leadership development* and another on *Family Voice and Leadership in Systems of Care*.

Repeated: Baby Powder Recall

The U.S. Food and Drug Administration (FDA) is alerting consumers about Johnson’s Baby Powder Lot #22318RB. A sample from this lot was found to contain chrysotile fibers, a type of asbestos. On October 18, 2019, Johnson & Johnson voluntarily recalled this product, and consumers who have this lot of baby powder should stop using it.

NOTE:

- **The 2020 Open Enrollment Period under the ACA is Nov. 1 through Dec. 15.** See www.HealthCare.gov and resources at the end of this Update.
- **The TRICARE and FEDVIP Open Season runs from Nov. 11 through Dec. 9.**
- **Medicare’s Medical and Drug Open Enrollment Period is Oct. 15 through Dec. 7.** See www.Medicare.gov.

UPCOMING WEBINARS AND CALLS

TODAY - NEW [Resources to Support Parent Leadership Development](#)

Wednesday, November 20, 12:30-1:30 pm ET

The [National Family Support Network](#) and [Be Strong Families](#)

Other webinars in this series:

- **[Uncovering America’s Best Kept Secret: Family Resource Centers and Family Support & Strengthening Networks](#)**
Wednesday, December 4, 12:30-1:30 ET

- [Introduction to the Standards of Quality for Family Strengthening & Support](#)
Wednesday, December 11, 12:30-1:30 ET

TODAY [Operationalizing Family Voice and Leadership in Systems of Care](#)

Wednesday, November 20, 2:30-4:00 pm ET

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

[Community Partnerships to Improve Access to Palliative Care, Hospice, and Bereavement Services](#)

Thursday, November 21, 12:00-1:00 pm ET

HHS Partnership Center and the National Hospice and Palliative Care Organization

NEW [The Intersection of Opioid Misuse and Disability--A Focus on Traumatic Brain Injury](#)

Thursday, November 21, 12:00-1:15 pm ET

National Association of State Head Injury Administrators (NASHIA)

NEW [Act Now! TRICARE Open Season, Federal Benefits Open Season Underway](#)

Thursday, November 21, 1:00-2:00 pm ET

TRICARE/Military OneSource

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

Thursday, November 21, 12:00-1:30 pm ET

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

NEW [The Art of Asking Questions](#) [for effective information and referral]

Thursday, November 21, 2:00-3:00 pm ET

[Alliance of Information and Referral Systems](#)

NEW [You're Not Alone: Embracing Struggles in Youth Engagement](#)

Friday, November 22, 2:30-4:00 pm ET

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

NEW [Will Washington Finally Act on Drug Prices?](#)

Tuesday, November 26, 2:00-3:00 pm ET

USC Annenberg Center for Health Journalism

NEW [Involving Families and Youth in Social Marketing](#)

Tuesday, December 3, 3:00-4:00 pm ET

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

NEW Stories from the Field – Building a Transformative Partnership with Families and Clinicians

Wednesday, December 11, 1:30-2:30 pm ET

Lucile Packard Foundation for Children's Health

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**

NEW Innovative Services in Home and Community-Based Services

Tuesday, December 17, 3:00-4:30 pm ET

Centers for Medicare and Medicaid Services (CMS)

THE COURTS

The decision is expected soon from the federal court of appeals in *Texas v. U.S.*, about the constitutionality of the Affordable Care Act.

THE ADMINISTRATION

Trump Administration Announces Historic Price Transparency Requirements to Increase Competition and Lower Healthcare Costs for All Americans

(CMS press release, 11/15/19):

If finalized, the [proposed Transparency in Coverage rule](#) would require health plans to:

- Give consumers real-time, personalized access to cost-sharing information, including an estimate of their cost-sharing liability for all covered healthcare items and services, through an online tool that most group health plans and health insurance issuers would be required to make available to all of their members, and in paper form, at the consumer's request. This requirement would empower consumers to shop and compare costs between specific providers before receiving care.
- Disclose on a public website their negotiated rates for in-network providers and allowed amounts paid for out-of-network providers. Making this information available to the public is intended to drive innovation, support informed, price-conscious decision-making, and promote competition in the healthcare industry. Making this information public directly helps the consumer, and importantly, creates new opportunities for researchers, employers, and other developers to build new tools to help consumers.

See also the CMS [fact sheet](#); [New Rule to Make More Health Care Rates Public](#) (Washington Post, 11/15/19). For a more detailed explanation, see [this Health Affairs blog post](#) (11/17/19).

CONGRESS

Budget and Appropriations

The “continuing resolution” (CR) that has been funding the government since the beginning of the fiscal year on October 1 is set to expire on November 21. To give appropriators more time to work out remaining issues, Congress is expected to pass another CR, which would last through December 20. That bill is expected to provide temporary funding of disproportionate share (DHS) payments to hospitals, community health centers, the National Health Service Corps, teaching health centers, a mental health demonstration program, and Medicaid funding for Puerto Rico and the other territories.

Prescription Drug Prices

It is not clear what form any prescription drug legislation might take - negotiations with drug companies versus some sort of price index (such as prices paid in other countries), or a combination of the two. See [Trump Officials Making Changes to Signature Drug Pricing Proposal, Azar Says](#); (The Hill, 11/13/19, 10:01 AM EST); [Pelosi Aide Hopeful White House Will Support Drug-Pricing Bill Despite Criticism](#) (The Hill, 11/13/19, 02:29 PM EST); [Compromise Could Be Brewing on Surprise Billing Ahead of Continuing Resolution](#) (Morning Consult, 11/8/19). For background information, see the [November 13 Update](#).

In related news, Senator Jeff Merkley (D-OR) and Richard Durbin (D-IL) have introduced the *End Price Gouging for Insulin Act* ([S.2817](#)), which has been referred to the Committee on Health, Education, Labor, and Pensions (HELP).

Surprise Medical Bills

As reported in earlier Updates, Congress is trying to address the issue of surprise medical billing. Although the issue is not partisan, it is controversial – insurers and providers have different ideas on how the problem should be addressed. According to the ranking Republican member of the Energy & Commerce Committee, however, a compromise is within view. See Ranking Member Greg Walden (R-OR) [press release](#) of November 18. For background information see [Compromise Could Be Brewing on Surprise Billing Ahead of Continuing Resolution](#) (Morning Consult, 11/8/19).

Related resource: [Navigator Guide FAQ of the Week: Help for Consumers Navigating a Surprise Balance Bill](#) (Georgetown Center on Health Insurance Reforms, 11/15/19)

MEDICAID/CHIP NEWS, INFORMATION, AND RESOURCES

Medicaid Fiscal Accountability Regulation

The Centers for Medicare and Medicaid Services (CMS) has released a [proposed regulation](#) that will limit certain ways - such as provider taxes - that states can raise money to fund their Medicaid programs. As explained by the National Association of Medical Directors (NAMD Update, 11/19/19):

On November 12, the Centers for Medicare and Medicaid Services (CMS) [issued a Notice of Proposed Rulemaking](#) (NPRM) on Medicaid fiscal accountability. The long-anticipated NPRM tackles a wide variety of Medicaid financing structures and mechanisms that CMS views as posing risks to the fiscal integrity of the program, including supplemental payment arrangements, provider taxes and donations, and sources of state share of Medicaid funding.

The rule proposes a number of new reporting requirements and practices that CMS argues will give it certainty in assessing and approving state financing arrangements, and directly responds

to concerns raised by federal oversight entities such as the Government Accountability Office and the U.S. Health and Human Services Office of the Inspector General. This NPRM was formally published in the Federal Register on November 18 with a 60-day comment period closing on January 17, 2020.

Updated “Core Set” for Child Quality Measures

On November 19, the Centers for Medicare & Medicaid Services (CMS) released an [Informational Bulletin](#) that describes the 2020 updates to the core set of children’s health care quality measures (the Child Core Set) for Medicaid and the Children’s Health Insurance Program (CHIP) and the core set of health care quality measures for adults enrolled in Medicaid (the Adult Core Set). [More information on Children's Health Care Quality Measures. Adult Core Set.](#)

2018 EPSDT Dataset Released

([Medicaid.gov Bulletin](#), 11/15/19):

On November 15, the Centers for Medicare & Medicaid Services (CMS) released the FFY 2018 [Form CMS-416 dataset](#). The dataset provides information on children’s receipt of Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services in all 50 states and Washington D.C. This data is reported by states to CMS. Send questions related to Form CMS-416 or the data to the EPSDT mailbox at EPSDT@cms.hhs.gov.

Other Regulatory Developments, as summarized by the National Association of Medical Directors (NAMD Update, 11/19/19):

- **CMS Bulletin Clarifies Medicaid TPL Responsibilities Modified by Statute**

On November 14, the Centers for Medicare and Medicaid Services (CMS) [issued an informational bulletin](#) providing technical updates to Medicaid's third-party liability (TPL) responsibilities. These updates clarify previous guidance on statutory modifications made by the 2018 Bipartisan Budget Act and provides clarification on further Medicaid and CHIP TPL statutory changes in April 2019 focused on timelines for payment on claims related to medical support enforcement.

- **CMS Guidance Describes Current and Planned Managed Care Contract Approval Process Improvements**

On November 8, the Centers for Medicare and Medicaid Services (CMS) published an [informational bulletin](#) outlining both current improvements to the Medicaid managed care contract approval process and future steps to further streamline the process. The bulletin, which responds to state-identified challenges with this process, details short-term solutions such as using redlined contract submissions to identify major changes in submissions, improving the timeliness of CMS communication with states to discuss contract changes, and developing a tip sheet for state reference. In the longer term, CMS aims to conduct a risk-based pilot review process, under which states that meet certain criteria with their current contracts would have a subsequent contract reviewed on an expedited basis.

- **CMS FAQ Provides Guidance on 1115 SMI Waivers**

On November 4, the Centers for Medicare and Medicaid Services (CMS) [published a set of Frequently Asked Questions \(FAQs\)](#) providing additional guidance to states on the parameters of the 1115 demonstration waiver for Serious Mental Illness (SMI) and Serious Emotional Disturbance

(SED), announced in November 2018. The FAQ focuses primarily on the average 30-day length of stay requirement for coverage of services in Institutions for Mental Disease (IMDs), outlining how states should report the average length of stay and the impacts on available FFP under the waiver if the 30-day limit is exceeded.

Georgetown Center for Children and Families (CCF)

CCF has information about the share of [children](#) and [adults](#) covered by Medicaid/CHIP *by Congressional district*. CCF has also developed an [interactive data hub](#) that provides state-specific information on how children are getting covered, their access to quality care, and policy options to improve enrollment and retention in Medicaid and CHIP.

WORTH REPEATING: 2019 Medicaid and CHIP Scorecard Released

On, November 7, the Centers for Medicare and Medicaid Services (CMS) released the second annual Medicaid & CHIP Scorecard. (See [CMS press release](#) and [fact sheet \[PDF version\]](#).) The Scorecard was developed to increase public transparency about the programs' administration and outcomes, and includes both measures voluntarily reported by states and federally reported measures. The Scorecard also includes [National Context](#) data that explain how Medicaid and CHIP programs can vary across states.

MEDICAID WAIVERS

Community-Based Care: How Medicaid Waivers Vary Across States

(Lucile Packard Foundation for Children's Health, Nov. 2019)

This report analyzes the scope of coverage offered under Medicaid home and community-based waivers and evaluates how states are using them to provide care for children with medical complexity. The researchers found great variability among states in services, and recommend some changes in age and diagnostic eligibility.

ACA NEWS, INFORMATION, AND RESOURCES

NOTE: The 2020 Open Enrollment Period is November 1, 2019 to December 15, 2019.

{FOR ENROLLMENT RESOURCES, PLEASE SEE THE END OF THIS UPDATE.}

Tens of thousands of Americans are about to lose their association health plans

(Washington Post's "The Health 202" blog, 11/15/19)

TRICARE

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 January 1, 2020.

For information on open season, see [Join Nov. 21 TRICARE Webinar on Open Season](#) (Benefits Update of 11/13/19, which provides links to other information). [Register](#) for the webinar.

For more information, please visit www.tricare.mil/OpenSeason or follow TRICARE on social media for regular updates:

- www.facebook.com/TRICARE
- www.twitter.com/TRICARE

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

OTHER NEWS, INFORMATION, AND RESOURCES

[Proposed Rule Regarding the Frequency and Notice of Continuing Disability Reviews](#)

From the Social Security Administration on 11/18/2019

This proposed rule would **affect SSI disability determinations**, including those for children.

From the Notice of Proposed Rulemaking:

[II. The Changes We Are Proposing](#)

We want to ensure that we continue to identify MI [medical improvement] at its earliest point through the CDR process. We also want to have the flexibility to adjust the scheduling of CDRs when there have been advances in treatment for a person's impairment(s) that improve the ability to work or, **for children receiving title XVI payments, that improve overall health and functioning.** *[Emphasis added.]* Therefore, we are proposing to make three changes to our current rules on when and how often we conduct CDRs. First, we propose to add a fourth medical diary category. ...The flexibility these proposed changes would allow us to determine MI at an earlier point than we can under our current rules. Consequently, we expect that the changes we are proposing would enhance program integrity and ensure that only those who continue to qualify for benefits will receive them.

From the SSA website:

- Background on the [Disability Determination Process](#) and [Disability Evaluation Under Social Security](#)
- [Child Disability Starter Kit](#)

[The Catalyst Center's State Data Chartbook Has Been Updated](#)

The Catalyst Center's [State Data Chartbook](#) presents selected indicators from all 50 states as well as Puerto Rico and the District of Columbia. It includes data from the National Survey of Children's Health, the Kaiser Family Foundation, the U.S. Department of Education, and other trusted sources, providing data on demographics, economics, child health services, insurance availability, and factors impacting health coverage and financing of care for Children and Youth with Special Health Care Needs (CYSHCN). Users can compare this data between states or against the national average for each indicator. A [tip sheet](#) outlines what the Chartbook has to offer and how the data may be used. The [Catalyst Center Glossary](#) offers a user-friendly introduction to key health care financing strategies and related terms. With questions about using the State Data Chartbook, glossary, or other Catalyst Center resources, contact the Catalyst Center at CYSHCN@BU.EDU.

Another useful resource: [Data in Action](#), from the Lucile Packard Foundation for Children's Health, which includes tips on using data to craft a message or tell a story, and tips for identifying good data.

From the National Academy for State Health Policy – reports:

[Medicaid Incentives, Performance Measures, and Workforce Innovations Foster Access to Pediatric Oral Health Care](#) (Nov. 15, 2019)

[State Medicaid Strategies to Promote Early Identification and Treatment of Pregnant Women with Substance Use Disorder](#) (Nov. 18, 2019)

From the National Resource Center for Patient/Family-Centered Medical Home –

podcast: [Gaining Ground: The Primary Care Pediatrician's Role in Public Health Systems of Care for CYSHCN](#). This three-part podcast series from the provides an overview of the history and functions of the **Title V** Maternal and Child Health/CYSHCN program, and highlights opportunities for partnerships between Title V programs and primary care physicians and families. Tools and resources are available.

From the Georgetown Center on Health Insurance Reforms (11/15/19):

[Navigator Guide FAQ of the Week: Help for Consumers Navigating a Surprise Balance Bill](#)

WORTH REPEATING: Report on Children’s Health Insurance Coverage

Last week, the Georgetown Center for Children and Families (Center) released its ninth annual report tracking children’s health insurance coverage ([overview](#); [full report](#); [blog post](#)). The Center also launched a [new interactive state data hub](#) showing a variety of indicators of children’s health status and quality of care. The report shows that, from 2016 to 2018, the number of uninsured children in the U.S. increased by more than 400,000.

WORTH REPEATING: NASHP Launches RAISE Act Family Caregiver Resource and Dissemination Center

With support from The John A. Hartford Foundation, the National Academy for State Health Policy has launched the [RAISE Act Family Caregiver Resource and Dissemination Center](#). The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act created the Family Caregiving Advisory Council, which is creating the country’s first national family caregiver strategy. The dissemination center will provide resources, technical assistance, and policy analysis for states and stakeholders to address this important issue.

WORTH REPEATING (again): [How States Use the National Standards for CYSHCN in their Health Care Systems](#) (map and state-specific information; National Academy for State Health Policy, 10/29/19)

YOUR INPUT SOUGHT

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

[Kaiser Family Foundation’s Medicaid Survey Highlights the Importance of Consumer Engagement](#) (blog of the Center for Community Engagement in Health Innovation, 11/12/19)

[An Illinois Health Insurer Rejected Out-Of-State Treatment for A 4-Year-Old’s Rare Disease Five Times. It Relented, But Why Is Getting an OK So Hard?](#) (Chicago Tribune, 11/18/19)

[13% Of Americans Say They Know Someone Who Died After They Couldn't Afford Health Care, Survey Says](#) (CNN, 11/13/19)

ACA OPEN SEASON RESOURCES

- **NEW:** [What Young Adults Should Know About Open Enrollment](#) (The Commonwealth Fund)
 - The audio and slides from the webinar - "[Best Practices When Assisting People with Disabilities Enroll in Health Coverage](#)" – part of the "Beyond the Basics" webinar series from the Center on Budget and Policy Priorities (CBPP), is now archived. The program's other resources can be found [here](#).
 - [Community Outreach Collaboratives](#) (COCs) work to increase collaborations in the community, dissemination and outreach efforts and enrollment of people with disabilities in the ACA marketplace. [Look for a COC](#) in your area.
 - Numerous enrollment resources are available on the website of the National Disability Navigator Resource Collaborative [here](#). at <https://nationaldisabilitynavigator.org/resources-links/#overview>.
 - [What's New for 2020 Marketplace Enrollment?](#) (Georgetown University Center on Health Insurance Reforms , 10/17/19) – provides an overview of several developments that affect this coming open enrollment.
 - **CMS FACT SHEET: FEDERAL HEALTH INSURANCE EXCHANGE 2020 OPEN ENROLLMENT** (describes new features of website)
 - [List of 2019 CMS Navigator grantees](#)
 - **The Georgetown Center on Health Insurance Reforms [Navigator Guide for Plan Year 2020](#).** The Guide helps answer questions about eligibility for insurance coverage or subsidies, health plan choices on- and off-marketplace, issues for small employers, coverage post-enrollment, and more.

Enrollment Assistance Materials from the Kaiser Family Foundation:

FAQs. To help consumers, navigators, brokers and other assisters, the Kaiser Family Foundation (KFF) has updated and expanded its database of more than 300 [Frequently Asked Questions](#) about open enrollment, the health insurance marketplaces, and the ACA. More than 180 of the FAQs are [available in Spanish](#). This year, there are new sections about immigration status, enrollment options for those affected by Hurricane Dorian, and the [sale of Marketplace plans on private websites](#), also known as "direct enrollment" sites or "certified enrollment partner" sites.

Fact Sheets. KFF also offers short, printable fact sheets on four common scenarios:

- [If You Shop on Private Websites Instead of HealthCare.gov](#)
- [If You Buy Health Coverage in the Individual Market](#)
- [For Consumers Considering Short-Term Policies](#)
- [If You Are Low-Income](#)

Calculator. KFF's Health Insurance Marketplace Calculator will soon be updated with 2020 premium data. Check [here](#) for KFF's most current resource.

Young Invincibles:

- [OE7 Resources and Suggested Messaging](#) (Scroll down for customizable materials, email message, FB posts, and Tweets.)
- [YI OE7 Materials Folder](#)
- [Connector tool](#) - find local help

Community Catalyst: [Outreach Hub](#) Google Drive

Center for Budget and Policy Priorities:

[5 Good Reasons to Visit HealthCare.gov During Open Enrollment](#) (full article) In sum:

1. Financial help is available to reduce the cost of coverage and care.
2. Plans are more affordable than people think.
3. Consumers can save money by comparison shopping on HealthCare.gov.
4. Plans purchased on HealthCare.gov are comprehensive and guaranteed to cover the essentials.
5. Beware of insurance plans sold outside of HealthCare.gov.

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. Modules for the first week of the *Helping Consumers Apply* 2020 Assister Readiness Webinar Series are now posted and ready to view:

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

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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