

GREETINGS FROM WASHINGTON, AND BEST WISHES FOR THE NEW YEAR!

It's a new year and a new Congress. The House of Representatives is now controlled by the Democratic Party, meaning that all committees are now chaired by Democrats and that the new (returned) House Speaker, Nancy Pelosi (D-CA), generally controls what measures will reach the House Floor. The Senate remains in Republican control. Also remaining from last year is the disagreement between the president and Congress about whether to fund a wall on the nation's southern border. Due to this impasse, a partial government shut-down began on December 22, and has no obvious end point as of this writing. Read about the shut-down, the court case challenging the Affordable Care Act, and other issues in this week's Update.

FDA: Teething and Sensory-Stimulation Jewelry Should Not Be Used

The Food and Drug Administration (FDA) issued an alert in December to advise parents and caregivers not to give such jewelry to their children. Its dangers include choking, strangulation, injury to the mouth, and infection. The <u>ALERT</u> includes advice for caregivers and health care providers, as well as information about how to report a problem caused by this jewelry.

<u>ACA Enrollment</u>: Due to Hurricane Michael, a Special Enrollment Period (SEP) has been established for certain individuals in **Florida** and **Georgia** so that they have more time to enroll in a health insurance plan. See the end of this Update for more information.

2019 Family Voices Leadership Conference Call for Presentations! (due Tuesday, Jan. 15) 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 <u>Call for Presentations Proposal</u>. Proposals are due by January 15, 2019. Questions? <u>Contact Beth Dworetzky</u>.

UPCOMING WEBINARS AND CALLS

NEW SERIES: Genetic Counselors in the Genomic Era –Public Health Genetics and Precision Medicine Roles

Sponsored by the National Society of Genetic Counselors (NSGC)

An Overview of Regional Genetics Networks
 Wednesday, January 9, 12:00-1:30 pm ET

Save the Dates:

- Direct-To-Consumer Genetic Testing
 Wednesday, February 6, 1:00-2:00 pm ET
- Disparities in Genetic Services and Privacy Tuesday, April 9, 12:00-1:00 pm ET
- Precision Medicine and Return of Results
 Tuesday, May 14, 12:00-1:00 pm ET

NEW The Integrated Care for Kids (InCK) Model

Wednesday, January 9, 2:00-3:00 pm ET

HRSA's Maternal and Child Health Bureau and CMS's Center for Medicare and Medicaid Innovation This webinar will provide guidance to MCHB grantees about how to be integrated in or engaged with CMS's new Integrated Care for Kids (InCK) Model.

Please register in advance at:

https://hrsa.connectsolutions.com/cms mchb registration/event/registration.html

Webinar link: https://hrsa.connectsolutions.com/cms-mchb_ic_for_km/

Dial-in Info: Dial-in: 800-369-2132 | Participant Code: 2307671

Questions: Contact Leandra Olson, lolson@hrsa.gov.

NEW <u>Findings from the 2018 National Survey of Information and Referral/Assistance</u> (I&R/A) Agencies

Wednesday, January 9, 3:00-4:30 pm ET.

The National Association of States United for Aging and Disability (NASUAD) and the National Council on Independent Living (NCIL)

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.

NEW Integrating Nurses into Complex Care Teams

Thursday, January 17, 1:00 pm ET

Better Care Playbook

NEW Introducing the Blueprint for Complex Care: Opportunities to Advance the Field

Tuesday, January 22, 2:00-3:00 pm ET

The National Center for Complex Health and Social Needs See the Blueprint for Complex Care.

NEW A New Approach to Assessing Family Engagement in Health Care Systems

Wednesday, January 23, 1:00 - 2:00 pm ET

Lucile Packard Foundation for Children's Health

It is suggested that participants read the recent issue brief from Family Voices, <u>A Framework for Assessing Family Engagement in Systems Change</u>, before the webinar. Audience Q&A is highly encouraged.

NEW NCAPPS Kickoff Webinar

Tuesday, January 29, 3:00- 4:30 pm ET

The Administration for Community Living and the Centers for Medicare & Medicaid Services

This webinar will provide an overview of the new National Center on Advancing Person-Centered

Practices and Systems (NCAPPS) and will provide details of the process for States, Tribes, and

Territories to apply for the first round of technical assistance. (More information is in the "Other News" section below.)

THE "SHUT-DOWN"

Health Programs

No doubt you have heard about the partial government "shut-down" caused by a stand-off between congressional Democrats and President Trump over whether to fund a "wall" that the president wants to erect on the nation's southwest border to prevent illegal immigration through Mexico. As a result of this disagreement, seven appropriations bills to fund a number of departments and agencies for the current (2019) fiscal year have not yet been enacted. Without funding, all but "essential" employees at these departments and agencies are prohibited from working, and even those who *are* working will not get paid until their departments'/agencies' appropriations bills have been enacted. Fortunately, the bill to fund the Departments of Labor, Health and Human Services, and Education was enacted before the stalemate occurred, so *most* health programs are not affected by the shut-down. See <u>What Does the Partial Government Shutdown Mean for Medicaid and CHIP?</u> (Blog of the Georgetown Center on Children and Families, 1/4/19); <u>How the Government Shutdown Affects Health Programs</u> (Kaiser Health News, 1/3/19).

There are some health programs that are affected, however. Appropriations for the **Indian Health Service** (IHS) are provided in the Department of Interior appropriations bill, which has not been enacted. During the shut-down, IHS can continue to staff and operate its hospitals and clinics but it is not able to provide the majority of funds for Tribes and Urban Indian Programs to operate their own facilities. Funding for the **Food and Drug Administration** (FDA) is provided through the Department of Agriculture appropriations bill, which is also on hold. One family is afraid that the shut-down will mean the loss of critical time in the trial of a new drug expected to cure their 6-year-old son's rare degenerative disease. See <u>Possible Lifesaving Medical Trial on Hold during Govt. Shutdown</u> (KARE

News, Minneapolis, MN, 1/8/19). For more details, see <u>FY 2019 HHS Contingency Staffing Plan for</u> Operations in the Absence of Enacted Annual Agriculture and Interior Appropriations.

Nutrition Assistance Programs

Nutrition assistance programs are part of the unfunded Agriculture Department. In a <u>January 8 press</u> <u>release</u>, Secretary of Agriculture Sonny Purdue announced that food stamps provided under the Supplemental Nutrition Assistance Program (SNAP) can be provided through February (by issuing the benefits by January 20). Benefits provided by the Special Supplemental Nutrition Program for Women, Infants and Children (WIC) will also continue through at least February. School meal programs can be funded through March, even if the shut-down continues. See <u>Food Stamps Guaranteed Through February</u>, <u>USDA Says</u> (CNN, 1/8/19). If the shut-down continues beyond February or March, it is not clear what will happen with these programs.

CONGRESS

The New Congress

The 116th Congress of the United States convened on January 3, 2019, and will exist for two years—divided into the first and second "sessions." It is the most racially and ethnically diverse Congress in history, and the most female. Among the new members are Native American women, Muslim women, and bisexual women, and a number of first-from-their-state women, people of color, or LGBTQ members. See Meet the New Freshmen in Congress (New York Times, 1/3/19). The House freshmen also include several health care professionals (physicians, a dentist and a nurse).

The most significant change from the last Congress is the fact that Democrats now hold the majority in the House of Representatives, meaning that all committee chairs are Democrats. (The Senate majority continues to be Republican.) Rep. Nancy Pelosi (D-CA) has been elected to serve as the Speaker of the House (her second stint), giving her control over which measures are taken up by the full House. Reps. Steny Hoyer (D-MD) and Kevin McCarthy (R-CA) return as the Democratic and Republican Majority Leaders, respectively.

Rep. Frank Pallone (D-NJ) will chair the Energy & Commerce Committee, which has jurisdiction over Medicaid, the Health Resources and Services Administration (HRSA), and the Indian Health Service, among other programs and agencies. Former committee chairman Greg Walden (R-OR) will be the Ranking Member. The Appropriations Committee will be chaired by Nita Lowey (D-NY), and the Subcommittee on Labor, Health and Human Services, and Education Appropriations will be chaired by Rep. Rosa DeLauro (D-CT). Rep. Richard Neal (D-MA) will chair the Committee on Ways & Means, which has jurisdiction over the Supplemental Security Income (SSI) program, taxes, Medicare, and other issues.

In the Senate, the **Finance Committee** will have a new chairman - Senator **Chuck Grassley** (R-IA) - due to the retirement of former chairman Orrin Hatch (R-UT). Senator Grassley served as Finance chairman previously, including when the committee passed the Family Opportunity Act of 2005, which created the federal grant program for Family-to-Family Health Information Centers. Senator **Ron Wyden** (D-OR), will continue to serve as the committee's ranking Democrat. There will be three new Republicans on the committee -- Senators James Lankford (R-OK), Steve Daines (R-MT), and Todd Young (R-IN) — and two new Democrats -- Maggie Hassan (D-NH) and Catherine Cortez Masto (D-NV).

Connecting With New and Returning Members of Congress

The beginning of a new Congress presents a great opportunity to establish contact with new Representatives and Senators and their staffers, and to reconnect with returning Members, who often have new staffers after an election. Family-to-Family Health Information Centers (F2Fs) can let congressional caseworkers (usually in the local office) know that their F2F is available to help constituents whose children have special health care needs. F2Fs can also let DC and local health staffers know that they can serve as a source of information about the needs of CYSHCN and their families in their state. You can find your two Senators at www.senate.gov, and your (one) Representative by entering your zip code at www.house.gov.

Status of Legislation

In the waning days of the last Congress, there were several bills of interest that were under consideration.

Not passed:

The Improving Medicaid Programs and Opportunities for Eligible Beneficiaries Act (IMPROVE Act, H.R. 7217; text) incorporated several Medicaid measures, including 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. The bill passed the House by a vote of 400-11 but was not taken up in the Senate before the end of the session. Some Senators opposed the temporary increase in the federal Medicaid matching rate that the ACE Kids Act would have provided to states that took up the health-home option.

Note: On January 4, 2019, Rep. Frank Pallone (D-NJ) introduced the Medicaid Extenders Act of 2019 (<u>H.R. 259</u>), which would extend for three months the **Money Follows the Person (MFP)** demonstration program and spousal impoverishment protections for Home- and Community-Based Services (HCBS) recipients.

The Emergency Medical Services for Children (EMSC) Program Reauthorization Act (<u>S. 3482</u>), had been passed by "unanimous consent" in the Senate, but was not taken up by the House before the end of the session. The <u>EMSC program</u>, administered by the Maternal and Child Health Bureau, provides grants to states and territories to improve their response to pediatric emergencies.

Signed by the president:

The Prematurity Research Expansion and Education for Mothers who deliver Infants Early ("PREEMIE") Reauthorization Act of 2018 (S. 3029) was signed by the president on December 18, becoming Public Law 115-328. The law reauthorizes 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.

The Improving Access to Maternity Care Act (H.R. 315), which requires HRSA to assign providers to areas with a shortage of maternity care health professionals, was signed by the president on December 17, becoming Public Law 115-320.

The Preventing Maternal Deaths Act of 2017 (H.R. 1318), which will provide funding to states and tribes to establish and improve maternal mortality review committees, was signed into law by the president on December 21, becoming Public Law 115-344.

The Traumatic Brain Injury Program Reauthorization Act (H.R. 6615), to reauthorize the Traumatic Brain Injury program, was signed by the president on December 21, becoming Public Law 115-377.

Upcoming Hearings

On January 3, House Energy and Commerce Committee Chairman Frank Pallone (D-NJ) <u>announced</u> the first three hearings to be held by the committee. The first hearing will be about climate change; the second will be about the impact of the federal district court decision that the Affordable Care Act is unconstitutional (see "Courts" section, below); the third hearing will be about the administration's former policy of separating immigrant families at the border and how the Administration is currently keeping immigrant children safe under the care of the Department of Health and Human Services.

THE COURTS

Update on <u>Texas v. Azar</u> -- Challenge to the ACA

As reported in the <u>last Update</u>, in December a federal district court held that the entire ACA is unconstitutional in <u>Texas v. Azar</u> (also known as <u>Texas v. United States</u>), a case brought by the attorneys-general in 20 Republican-led states . See <u>Texas Judge Strikes Down ACA as Unconstitutional</u>, <u>But Long Legal Path Remains</u> (FierceHealthcare, Friday, 12/14/18). The court "stayed" the ruling so that the ACA remains fully in effect pending appeals. On January 8, the Department of Justice asked for a delay in proceedings due to the government shut-down.

Attorneys-general from 17 Democratic-led states and DC have been granted the right to intervene as parties to the case, arguing that the entire law should be upheld, and have <u>filed an appeal</u> with the U.S. Court of Appeals for the 5th Circuit. The Department of Justice <u>also appealed</u> since it does not agree with the district court that the *entire* ACA should be repealed, even though the administration has chosen not to defend major parts of the law.

In the past week, Democrats in the House of Representatives filed motions in the district court and appeals court to intervene as parties in the case in support of the ACA. See <u>House Formally Moves to Intervene in Obamacare Lawsuit</u> (The Hill, 1/4/19). For legal details see <u>Latest Enrollment Numbers;</u> <u>Dem States, DOJ Appeal Texas to 5th Circuit</u> (Health Affairs blog, 1/7/19).

It could take many months for the appeals court to act, and then the case <u>might be taken up</u> by the Supreme Court, which would not be able to hear the case until its October 2019 term at the earliest. In theory, Congress could amend the ACA in order to make the case moot before it reaches that point. <u>Congress Could Get Rid of ACA Lawsuit, But Won't</u> (Axios, 12/18/18).

MEDICAID AND CHIP NEWS, INFORMATION AND RESOURCES

Managed Care Comments Due on January 14

As reported earlier, and explained in the "Your Input Sought" section below, the administration issued a <u>proposed rule on Medicaid/CHIP managed care</u> on November 14. Comments are due on January 14. See <u>Proposed Changes to Medicaid Managed Care Rule Will Reduce Access to Providers</u> (short post on

the blog of the Georgetown Center on Children and Families, 12/6/18); <u>Inside the Trump</u> <u>Administration's Proposed Medicaid Managed Care Rule</u> (long post on the Health Affairs blog, 12/5/18).

MEDICAID WAIVERS

In late December, CMS approved Medicaid §1115 waivers for Michigan, Maine, Kansas and New Mexico. Although the Kansas "KanCare" extension was approved through 2023, the state's request to establish a work requirement and time limit were not approved. The federal comment period for Virginia's waiver proposal ended on January 6. That proposal includes a work requirement, increased premiums and cost-sharing. The federal comment period is open until January 18 for Oklahoma's waiver proposal, which also includes a work requirement.

<u>Tennessee</u> proposes to amend its demonstration to add community-engagement requirements as a condition of eligibility for certain individuals age 19 through 64 who are enrolled in the parent/caretaker relative eligibility group. The federal public comment period for that proposal is open until February 7. For updates on §1115 waiver proposals see the Kaiser Family Foundation's <u>Medicaid Waiver Tracker</u>: <u>Approved and Pending Section 1115 Waivers by State</u> (last updated January 3).

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.

TRICARE

New to TRICARE? The Basics You Need to Know

Jan. 3, 2019

Calendar Year Costs for TRICARE Resets Jan. 1

Dec. 18, 2018

TRICARE implemented in 2018 include changing cost limits from a fiscal-year cycle to a calendar-year cycle. Therefore, annual catastrophic caps and deductibles will reset every January 1.

Need Health Advice? Talk to a Registered Nurse Anytime

Dec. 26, 2018

With the Military Health System (MHS) Nurse Advice Line, TRICARE beneficiaries can get advice from a registered nurse anytime, 24/7.

Sign up for TRICARE email updates at www.tricare.mil/subscriptions. Connect with TRICARE on Facebook and Twitter at www.facebook.com/tricare and www.twitter.com/tricare.

OTHER NEWS, INFORMATION, AND RESOURCES

New National Center on Advancing Person-Centered Practices and Systems

The <u>Administration for Community Living</u> and the <u>Centers for Medicare & Medicaid Services</u> recently announced the launch of the National Center on Advancing Person-Centered Practices and Systems

(NCAPPS). The goal of NCAPPS is to promote systems change to implement person-centered principles. The Center will assist states, tribes, and territories to transform their long-term care service and support systems to implement U.S. Department of Health and Human Services policy on person-centered thinking, planning, and practices. Activities will include providing technical assistance to states, tribes, and territories; establishing communities of practice to promote best practices; hosting educational webinars; and creating a national clearinghouse of resources to support person-centered practice. NCAPPS is funded by the Administration for Community Living and the Centers for Medicare & Medicaid Services, and administered by the Human Services Research Institute (HSRI). A Person-Centered Advisory and Leadership Group composed of national experts with lived experience receiving long-term services and supports will oversee and contribute to all aspects of NCAPPS. HSRI will be partnering with national organizations to ensure the work is relevant and effective. States, tribes, and territories can apply for technical assistance through an online application. The deadline is February 12, 2019. Completed applications should be submitted to NCAPPS@acl.hhs.gov. For more information see the NCAPPS overview document, participate in the January 29 webinar (see "Upcoming Webinars" section above), or contact NCAPPS@acl.hhs.gov.

YOUR INPUT SOUGHT

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.

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.

Medicaid §1115 Waivers – State waiver proposals are subject to both state and federal comment periods. See the "Medicaid waivers" section above for open federal comment periods.

Additional Special Enrollment Period Available for Victims of 2018 Hurricane Michael (From CMS)

Note: This message is intended for Georgia and Florida assisters only

The Centers for Medicare & Medicaid Services (CMS) is providing additional opportunities to enroll in Federally-facilitated Exchange (FFE) coverage for certain individuals affected by Hurricane Michael in Florida and Georgia.

In early October 2018, CMS issued press releases that announced the availability of a Special Enrollment Period (SEP) for certain individuals who were seeking coverage in Qualified Health Plans (QHPs) through the FFE and who were impacted by Hurricane Michael. The press releases referenced the <u>August 2018 CMS Guidance on Special Enrollment Periods</u> (SEPs) related to Emergency and Major Disaster Declarations by the Federal Emergency Management Agency (FEMA).

Individuals eligible for a SEP related to this guidance have up to 60 days from the end of the FEMA-designated incident period to select a new QHP through the FFE or to make changes to their existing QHP enrollment. In Florida, the end of the SEP was December 18, 2018, and in Georgia, it was December 22, 2018.

On December 21st, we further <u>announced</u> that individuals in the Florida and Georgia counties that FEMA designated as eligible to apply for "individual assistance" or "public assistance" under a major disaster declaration due to Hurricane Michael who were unable to enroll during an enrollment period for which they were eligible will have an additional 60 days after the end of the first Hurricane Michael SEP to enroll in coverage. In <u>Florida</u>, eligible consumers will have until February 16, 2019 to enroll. **Exchange coverage.** In <u>Georgia</u>, qualifying consumers will have until February 20, 2019 to enroll.

Who is Eligible?

To enroll in coverage under this SEP, individuals must contact the Marketplace Call Center at 1-800-318-2596 or TTY at 1-855-889-4325, and attest that they meet the following eligibility requirements:

- They resided in any of the counties that are eligible to apply for "individual assistance" or
 "public assistance" by FEMA either during the FEMA-designated incident period for the major
 disaster for Hurricane Michael, or at the time of application for enrollment; and
- They were affected by the disaster, and that it prevented them from completing enrollment. For a list of Florida counties that FEMA designated as eligible to apply for "individual assistance" or "public assistance" under a major disaster declaration due to Hurricane Michael, see: https://www.fema.gov/disaster/4399.

For a list of Georgia counties that FEMA designated as eligible to apply for "individual assistance" or "public assistance" under a major disaster declaration due to Hurricane Michael, see: https://www.fema.gov/disaster/4400.

What documentation is needed?

Marketplace SEP pre-enrollment verification requirements may be waived for consumers who are eligible for this SEP. Consumers must attest that they live or did live in the impacted area during the FEMA major disaster declaration for Hurricane Michael and were unable to complete enrollment

within 60 days from the end of the first SEP offered related to the Hurricane. No further documentation is needed.

Steps to helping a consumer access this SEP:

- 1. Help the consumer complete a 2018 and/or 2019 Marketplace application online, depending on their needs, at HealthCare.gov. After completing the online application, the consumer may receive an Eligibility Determination Notice stating that he or she is not eligible to enroll in 2019 coverage because the Open Enrollment period for 2019 has ended.
- 2. Next, help the consumer call the Marketplace Call Center (no later than February 16, 2019, if you are in Florida, or February 20, 2019, if you are in Georgia). Inform the consumer to let the Call Center representative know that he/she was impacted by Hurricane Michael and was unable to apply for 2018 coverage using a SEP for which he/she was eligible or 2019 coverage during Open Enrollment or using a SEP for which he/she was eligible.
- 3. Each SEP request will be evaluated by a Marketplace Caseworker, which may take several days. Caseworkers will review an individual's eligibility for the SEP using available information from Marketplace consumer records and public information on FEMA declarations.

Once the Marketplace determines his/her SEP eligibility, the consumer will receive a notice by mail with his/her result. If he/she was determined SEP eligible, you can then help the consumer go back to HealthCare.gov and select a plan.

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 iguerney@familyvoices.org.

Yours truly,
Janis Guerney
Director of Public Policy
Family Voices

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