

Greetings from Washington, DC!

There are two big news items in the health policy world this week:

- The Supreme Court lifted an injunction that had been stopping implementation of the administration's "public charge" rule, but only while appeals are pending.
- The Centers for Medicare and Medicaid Services (CMS) will be unveiling guidance to states on how they can "block grant" or receive per capita caps for coverage of certain adults.

Of course, in the medical world, there is other big news – about the novel coronavirus that emerged in China. You can keep up to date on this topic via the <u>CDC's webpage on the novel coronavirus from</u> <u>China</u>. See also <u>Coronavirus Misinformation Is Spreading Fast</u> (Axios Vitals, 1/28/20).

REMINDERS: See the "Your Input Sought" section below for details and information about how to submit comments on the following:

- Due **Friday, 1/31** comments on proposed rule to require *more frequent disability reviews for some children on SSI*
- Due Friday, 2/7 comments on family caregiving concerns and recommendations
- Due Friday, 2/7 comments on grandparents raising grandchildren

Miscellaneous info for families:

<u>Prevent CO Poisoning</u> | <u>En Español.</u> Carbon monoxide (CO) poisoning is entirely preventable. Protect yourself and your family by learning the symptoms of CO poisoning and how to prevent it.

UPCOMING WEBINARS AND CALLS

Genuine Resilience is Closer (and Easier) Than You May Think

Wednesday, January 29, 2:00 pm ET National Caregiver Alliance

Communication Partnerships for Public Health Emergencies

Wednesday, January 29, 1:00-2:00 pm ET Centers for Disease Control and Prevention (CDC)

From Coverage to Care: How to Use Health Coverage

Thursday, January 30, 1:00-2:00 pm ET *CMS Office of Minority Health*

Ask TRICARE

Thursday, January 30, 1:00-2:00 pm ET

TRICARE/ Military OneSource For more information, see <u>Bring Your TRICARE Benefit Questions to Jan 30 Webinar</u>.

SERIES Person-Centered Planning and Practice

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

- Monday, February 3, 12:30-3:00 pm ET
- Monday, June 1, 1:00-3:30 pm ET
- [past] Friday, September 6, 2019
- [past] Friday, December 13, 2019
- [past] Monday, January 6

Special Enrollment Periods (ACA)

Thursday, February 6, 2:00 pm ET <u>Health Reform: Beyond the Basics</u>/Center on Budget and Policy Priorities

NEW <u>Moving Forward: Using the National CLAS Standards to Address Social Justice</u> and Health Equity

Thursday, February 6, 1:30-3:00 pm ET SAMHSA's National TA Network for Children's Behavioral Health

NEW <u>Cultural and Linguistic Competence Learning Community Round Table and Office</u> Hours

Friday, February 7, 2:00-3:00 pm ET SAMHSA's National TA Network for Children's Behavioral Health

Family Caregiving Policies and Innovations

Thursday, February 20, 2:00 pm ET RAISE Family Caregiver Resource and Dissemination Center, National Academy for State Health Policy (NASHP)

REACH for Transition: Developing Independence: Supported Decision-Making, Part 1: Helping Youth/Youth Adults Take Charge of Their Healthcare

Tuesday, February 25, 12:00-1:00 pm ET SPAN Parent Advocacy Network

NEW <u>Innovative Strategies for Outreaching and Engaging Young People in Behavioral</u> <u>Health Services</u>

Tuesday, February 25, 2:00-3:30 pm ET SAMHSA's National TA Network for Children's Behavioral Health

Marketplace Appeals Process (ACA)

Tuesday, February 25, 2:00 pm ET <u>Health Reform: Beyond the Basics</u>/Center on Budget and Policy Priorities

Parent Peer Support Providers: Roles Across Systems and Service Level Intensity

Thursday, February 27, 3:00-4:30 pm ET Substance Abuse and Mental Health Services Administration (SAMHSA) TA Network

THE COURTS

Supreme Court Allows Administration to Enforce "Public Charge" Rule, Pending Appeal

On January 27, the <u>Supreme Court lifted a nationwide-ban</u> (injunction) on enforcement of the "public charge" rule, *pending further appeals.* This means that the administration can start enforcing the rule (except in Illinois, where there is a statewide injunction), although it still may be struck down eventually. The "public charge" rule would make it easier for the government to deny green cards or entry visas to people deemed to be at risk of becoming a "public charge," i.e., dependent on public benefits. It is important to remember that the rule does NOT affect children's eligibility for Medicaid or other programs, and that a child's use of such programs will NOT be held against his/her family members. See this fact sheet about the rule, and this Reuters story about the Supreme Court decision. For more legal details, see this post on SCOTUSblog. A resource for families: Should I Keep My Kids Enrolled in Health and Nutrition Programs?

The injunction against enforcing the rule could be re-instituted in the future. A case on that issue will be heard as early as next month in U.S. Court of Appeals for the Second Circuit (based in NY). That case could be further appealed to the Supreme Court. Ultimately, the courts will rule on the validity of the rule itself.

THE ADMINISTRATION

CMS Guidance Allowing States to Partially "Block Grant" their Medicaid Programs

On Thursday, January 30, the administration plans to unveil new guidance on how states can partially restructure their Medicaid programs by receiving fixed amounts to cover adults in the "expansion population" (childless adults that states have the option to cover under Medicaid pursuant to the Affordable Care Act). Currently, states receive federal payments based on what they actually spend. A one-hour, live-stream <u>presentation</u> about the guidance - *Transforming Medicaid: A New Opportunity for Better Health* - will begin Thursday, January 30, at 10:30 AM EST. For more information, see <u>Trump Administration Finalizing Medicaid Block Grant Plan Targeting Obamacare</u> (Politico, 1/23/20), and <u>Trump Administration to Offer States Medicaid Block Grant Option</u> (Washington Post, 1/28/20).

CONGRESS

Hearing on Paid Family Leave

On January 28, the House Ways & Means Committee held a <u>hearing</u> on paid family leave. Committee member Rep. Bill Pascrell (D-NJ) illustrated the benefits of paid family leave with the story of Lauren Agoratus, of the NJ F2F and Family Voices Affiliate. The hearing can be watched <u>here</u>. (Rep. Pascrell's remarks begin at ~2:28:00; he mentions Lauren's story at ~2:30:10.) The public can submit comments

for the hearing record through close of business on February 11. See <u>instructions for submitting</u> <u>comments</u>.

MEDICAID/CHIP NEWS, INFORMATION, AND RESOURCES

<u>WORTH REPEATING</u>: Request for Information on Out-of-State Provision of Medicaid Services for Children with Medically Complex Conditions

On January 21, the Centers for Medicare and Medicaid Services (CMS) published a <u>Request for</u> <u>Information</u> on "Coordinating Care from Out-of-State Providers for Children with Medically-Complex Conditions." CMS is seeking public comments on:

- Best practices for using out-of-state providers in coordinating care for children with medically complex conditions;
- How care is coordinated for such children when that care is provided by out-of-state providers including when care is provided in emergency and non-emergency situations; and
- Processes for screening and enrolling out-of-state providers, including efforts to streamline these processes or reduce the burden of these processes on such providers and states.

Comments are due on March 23.

WORTH REPEATING: Medicaid and State Budgets: Checking the Facts (Yet Again)

Blog post from the Georgetown Center for Children and Families, 2/28/19 This year-old blog post is worth reviewing, as it explains how to assess the portion of a state's own funds spent on the Medicaid program – a large figure, but lower than it may seem from some reports.

MEDICAID WAIVERS

See "Administration," above, about the administration's guidance for states to request Medicaid "block grants" or per capita caps for childless adults.

Pending State Waiver Requests

Georgia. Georgia has submitted a new, five-year <u>Sec. 1115 demonstration proposal</u> to CMS that would create a **new eligibility group restricted to individuals with incomes between 35 percent and 100 percent FPL who work at least 80 hours a month**. Those with incomes above 50 percent FPL would also have to pay a monthly premium to maintain eligibility. The <u>federal comment period</u> is open until **February 7, 2020.**

Idaho. On January 3, 2020, Idaho requested a new 5-year <u>section 1115 demonstration</u> that would allow the state to receive federal financial participation for inpatient, residential, and other services provided to otherwise-eligible Medicaid beneficiaries while residing in **institutions for mental diseases** (IMD) for diagnoses of substance use disorder (SUD) and/or serious mental illness (SMI)/serious emotional disturbance (SED). Federal public <u>comments can be submitted</u> through February 8, 2020.

Illinois. Illinois has submitted an application for a <u>new 5-year section 1115 demonstration</u> seeking authority for three initiatives: (1) Extension of the postpartum coverage from 60-days to 12-months;
(2) Managed care organization (MCO) reinstatement for Medicaid beneficiaries who submit late

redetermination paperwork within 90-days; and (3) **The waiving of hospital presumptive eligibility (HPE)**. <u>Comments can be submitted</u> through **February 13, 2020.**

Waiver Updates:

- <u>Medicaid Waiver Tracker: Approved and Pending Section 1115 Waivers by State</u> (Kaiser Family Foundation)
- <u>A Snapshot of State Proposals to Implement Medicaid Work Requirements</u> (National Academy for State Health Policy)

ACA NEWS, INFORMATION, AND RESOURCES

NOTE: The open-enrollment period for plans sold on the federally facilitated exchanges (healthcare.gov) has ended, but some state marketplaces are still open:

- District of Columbia: January 31, 2020
- New York: January 31, 2020

TRICARE

From TRICARE Benefits Updates:

- Looking for Answers? TRICARE Publications Can Help (1/22/20)
- How TRICARE for Life Eligibility, Enrollment Works (1/27/20)

More TRICARE info can be found at <u>www.facebook.com/TRICARE</u> and <u>www.twitter.com/TRICARE</u> Or <u>Sign up for TRICARE email updates</u>.

OTHER NEWS, INFORMATION, AND RESOURCES

<u>FindTreatment.gov</u>. This newly designed website from the Substance Abuse and Mental Health Services Administration (SAMHSA) helps people find substance abuse treatment. Visitors can enter a ZIP Code to find local state-licensed facilities, treatment options, payment and insurance information, and what to expect on the first call.

<u>USA.gov</u> provides a broad range of information about the federal government, including <u>tips and</u> <u>resources</u> for caregivers of adults and/or children living with a disability. The site provides information on how to get help and support, as well as how to get paid as a caregiver. For example, the <u>Medicaid</u> <u>Self-Directed Care Program</u> allows some family members of people with disabilities to get paid for caring for them.

WORTH REPEATING: New Resource on Family Engagement

Family Voices, in partnership with experienced family leaders and professional partners from community, academic, public health, and pediatric settings, has developed a <u>Family Engagement in</u> <u>Systems Assessment Tool</u> (FESAT) for assessing and improving family engagement in child- and family-serving organizations. A recent webinar about the FESAT discusses how it can be used with organizational partners to assess and improve family engagement in systems-level initiatives. <u>Click here</u> for links to the slide deck, webinar recording, and to download the FESAT.

WORTH REPEATING: Parity in Practice? Examining Requirements and Enforcement of the Mental Health Parity and Addiction Equity Act

Blog of the Georgetown Center on Health Insurance Reforms, 1/13/20

YOUR INPUT SOUGHT

Please see above section on Medicaid waivers to comment on state waiver proposals.

Proving Disability More Frequently – Due January 31

As reported in earlier Updates, the Social Security Administration has issued a proposed rule -<u>Proposed Rule Regarding the Frequency and Notice of Continuing Disability Reviews</u> under which "continuing disability reviews" (CDRs) would be conducted more frequently for people with certain conditions, including children with certain behavioral conditions, cancers, asthma, and some other conditions. Additional reviews may also be required when children are nearing ages 6 and 12. Comments can be submitted easily via <u>this page on Regulations.gov</u>.

Input Sought from Family Caregivers – due February 7

The Administration for Community Living (ACL) is seeking input, from individuals and organizations, on the challenges faced by family caregivers and ideas about how to address them. This information will be used to assist the <u>RAISE Family Caregiving Advisory Council</u> in developing a national family caregiving strategy and planning future activities, including public listening sessions that will begin this year. For more information and to provide your input, please complete this **FORM** by 11:59 p.m. EST on Friday, February 7, 2020. (Note that commenters are asked for their first names only. Each online comment form is for only one issue, but commenters can easily submit multiple forms.)

NEW: Request for Input about Grandparents Raising Grandchildren – due Feb. 7

The Administration for Community Living (ACL) is requesting information to assist the <u>Advisory Council</u> to <u>Support Grandparents Raising Grandchildren</u> in developing an initial report to Congress, which will include best practices, resources, and other useful information for grandparents and other older relatives raising children. See the <u>Federal Register notice</u>. ACL seeks public input on information, resources, programs, and/or best practices to help grandparents, other relatives, and kinship caregivers. It is also requesting information about gaps and/or unique needs related to specific caregiver populations, such as Native Americans. **Comments are due by 11:59 p.m. EST on February 7, 2020.** More information and a form to submit comments can be found on <u>this webpage</u>.

Organ Donation Regulations – due February 21, 2020

On December 17, the administration announced a proposed rule intended to increase the number of organ donations. For more information, see the press release, <u>Organ Procurement Organization (OPO)</u> <u>Conditions for Coverage Proposed Rule: Revisions to Outcome Measures for OPOs</u>, and <u>Trump</u> <u>Administration Announces Move Aimed to Increase Organ Donations</u> (The Hill, 12/17/19). **The proposed regulation can be found, and comments can be submitted on** <u>Regulations.gov</u>.

DOT Seeks Input on Proposal to Make Airplane Lavatories More Accessible – due March 2

The U.S. Department of Transportation (DOT) seeks public comments on a new <u>proposed rule</u> to improve restroom access for passengers with disabilities on single-aisle aircraft with 125 or more seats. The rule is based on <u>negotiated rulemaking</u> undertaken by DOT's Advisory Committee on Accessible Air Transportation, which included aviation industry representatives, disability rights advocates, and other stakeholders. The proposed regulation addresses lavatory interiors, on-board wheelchairs, and training of flight attendants. **Comments are due by March 2, 2020, and can be submitted** <u>here</u>.

FDA Patient Representatives

Are you a patient or caregiver who wants to get involved at FDA? Contact <u>the Patient Affairs Staff (PAS)</u> or follow them on Twitter <u>@FDAPatientInfo</u>.

Submit stories about how Medicaid has helped you to "That's Medicaid"

Through its "<u>That's Medicaid</u>" initiative, the Robert Wood Johnson Foundation is publicizing stories about how Medicaid has helped people in various situations. These stories might be helpful as you educate policymakers and the public about Medicaid. People can submit their own Medicaid stories <u>here</u> (scroll down).

OF POSSIBLE INTEREST

- <u>Unusual Study Details Woes Among Veterans of Foster Care</u> (Associated Press, 1/22/20)
- <u>Everybody Covered What the U.S. Can Learn from Other Countries' Health Systems</u> (Vox, 1/13/20)
- <u>How Greta Thunberg's Autism Helped Make Her the World's Most Important Person for 2020</u>, from The Hill, *Changing America* [opinion]

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 <u>jguerney@familyvoices.org</u>.

Yours truly, Janis Guerney Director of Public Policy Family Voices

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