



FAMILY VOICES[®]

Washington DC Update
July 25, 2019

GREETINGS FROM WASHINGTON!

As you can see below, there is a lot going on in Congress right now, as Members try to get things done before they leave DC for the annual August recess. Speaking of which...**Time to meet with your Members of Congress at home!**

Meet with your Members of Congress during the August recess. Members of Congress will be back at home in August, and it's not too early to make an appointment to see them. In fact, it's a good idea to make an appointment as soon as possible. You can find the local-office numbers for your Members of Congress at www.contactingcongress.org. And check <https://townhallproject.com/> to find town halls and other public events where you might be able to see your Representative or one of your Senators. Their time at home provides a great opportunity to educate them about the needs of children and youth with special health care needs (CYSHCN) and their families. You can also educate them about your state's Family-to-Family Health Information Center, and let them know how federal policies affect your children and family. To make your messages more memorable, go with other families and bring your children (or photos of them). For more information on recess visits, check out the **July 26 (Friday) webinar on [How to Engage When Legislators Are Out of Session](#)**. If you want to brush up on how a bill becomes a law, check out [The Essential Guide to Legislation](#) (from Politico Pro).

ADA and Medicaid/Medicare Birthdays

July is a significant month when it comes to health and disability policy. The Americans with Disabilities Act (ADA) was enacted 29 years ago on July 26. Medicaid and Medicare were enacted 54 years ago on July 30.

- **ADA Anniversary, July 26** – [resources for anniversary, background on ADA](#)
- **Medicaid Anniversary, July 30** – [Community Catalyst Medicaid Birthday Toolkit](#)

REMINDERS: The Centers for Medicare and Medicaid Services (CMS) has issued the Notice of Funding Opportunity (NOFO) for the Federally-facilitated Exchange (FFE) Navigator Program, and the [Application Link](#) is now live to apply to be a "Certified Designated Organization" to assist people with getting insurance through the Affordable Care Act (ACA). (See the "ACA" section below.)

UPCOMING WEBINARS AND CALLS

[Culturally Competent Direct Care: Meeting The LTSS Needs Of Diverse Dually Eligible Beneficiaries](#)

Thursday, July 25, 12:30-2:00 pm ET

Resources for Integrated Care

[TRICARE Webinar on TRICARE Coverage after Retirement](#)

Thursday, July 25, 1:00-2:00 pm ET

TRICARE; Military OneSource

[Evidence for the Impact of Money Follows the Person \(MFP\)](#)

Thursday, July 25, 2:00-3:30 pm ET

Brandeis University

Email: clpolicy@brandeis.edu if you have any questions or need any further accommodations.

NEW [How to Engage When Legislators Are Out of Session](#)

Friday, July 26, 12:30 pm ET

Phone2Action

[Growth and Development: Capitalize on New Business Opportunities](#)

Wednesday, July 31, 12:30-1:30 pm ET

Administration for Community Living HCBS Business Acumen Center

Topic: How to assess your organization's financial position to move into new contract arrangements and what you specifically need to focus on to work with managed care organizations.

[Technical Assistance webinar: HRSA Early Hearing Detection and Intervention \(EHDI\) Program Notice of Funding Opportunity \(NOFO\)](#) [link at below date, time]

Wednesday, July 31, 2:00 pm ET

Health Resources and Services Administration (HRSA)

Call-In Number: 1-888-889-2042

Participant Code: 1398484

[Question and Answer Session: Disability-Competent Care Conversation on Access with ADANN \(Americans with Disabilities Act National Network\)](#)

Wednesday, July 31, 2:00-2:30 pm ET

The Lewin Group, in collaboration with ADANN

NEW -- [Web Meetings: Person-Centered Planning and Practice Standing Committee \(quality measurement\)](#)

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

- **Wednesday, July 31, 2:30- 5:00 pm ET**
- **Friday, September 6, 2019, 1:00-3:30 pm ET**

- 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

SERIES: #ABLEtoSave Awareness Campaign

ABLE National Resource Center

First webinar: [Welcome to #ABLEtoSave Month: An Orientation on What You Need to Know About ABLE](#)

Thursday, August 1, 2:00-3:00 pm ET

Future webinars:

- Week 1: August 8: Opening an ABLE Account: Key Decisions for Success
- Week 2: August 15: ABLE Best Practices and Action Steps for Family Members and Supporters (Circle of Support)
- Week 3: August 22: ABLE Best Practices for Working-Age Adults
- Week 4: August 29: Celebrating All the Ways You are ABLE: Announcing Winners from #ABLEtoSave Video Contest and Next Steps!

NEW [Why Being Brain Injury Informed Is a Critical Component of Person-Centered Thinking, Planning, and Practice](#)

Monday, August 12, 3:00-4:30 pm ET

National Center on Advancing Person-Centered Practices and Systems (ACL and CMS)

THE COURTS

[Federal Judge Upholds Trump's Expansion of Non-Obamacare Plans](#)

(The Hill, 07/19/19)

Via regulation, the administration allows sales of “short-term” health insurance plans that are effective for up to a year. Such plans generally are less expensive than standard ones because they do not need to offer the full range of benefits otherwise required by the Affordable Care Act (ACA), and can deny or charge more for coverage for people with pre-existing conditions. On July 19, a federal district court judge ruled against the plaintiff, the Association for Community Affiliated Plans, finding that it had not proved that it lost customers as a result of the regulation. As a result, insurers can continue to see short-term health plans.

CONGRESS

Congress and the Administration Reach Budget Deal

On July 22, House Speaker Nancy Pelosi and Treasury Secretary Steve Mnuchin reached a budget deal that will increase both defense and non-defense “discretionary” (appropriated) spending for federal fiscal years 2020 and 2021 (until Oct. 1, 2021). The deal also suspends the nation’s debt ceiling until July 31, 2021, averting a feared, unprecedented default on the national debt until later that year. Without a deal to “lift the caps” on spending, there would have been automatic appropriations cuts (“sequestration”) under a 2011 budget deal. Those caps have been lifted in the past, as well, although

some automatic cuts have taken place in mandatory spending (non-appropriated) programs, including the Family-to-Family Health Information Center grant program. While the president and the House and Senate Republican Leaders have endorsed the deal, Members of Congress who are stronger “deficit hawks” [oppose](#) it, and others are concerned about certain aspects of it. Nevertheless, Congress is to approve the deal before the August recess. See [Deal Sealed on Federal Budget Ensures No Shutdown, Default](#) (Associated Press, 7/23/19); [Trump Announces Support for Two-Year Bipartisan Budget Deal That Boosts Spending, Suspends Debt Limit](#) (Washington Post, 7/23/19); [White House, Hill Leaders Agree on Two-Year Budget Deal](#) (Roll Call, 7/22/19).

House Consideration of Autism CARES and Other Health Bills

On July 24, the House approved several health-related bills:

- [H.R. 2035](#) – Lifespan Respite Care Reauthorization Act of 2019, as amended
- [H.R. 776](#) – Emergency Medical Services for Children Program Reauthorization Act of 2019
- [H.R. 1058](#) – Autism CARES Act of 2019
- [H.R. 2507](#) – Newborn Screening Saves Lives Reauthorization Act of 2019, as amended

As reported in [the July 19 Update](#), these bills were reported out of the House Energy & Commerce Committee last week, along with the legislation to extend funding for Family-to-Family Health Information Centers (F2F), community health centers, and other programs. Unlike the F2F program and some of the other programs, however, the programs authorized by the above bills must go through the appropriations process to receive funding.

Money Follows the Person Bill Becomes Law

On July 24, the president signed the *Medicaid Extenders Act of 2019* ([H.R. 259](#); Pub. Law 116-3), which funds and revises the Money Follows the Person Rebalancing Demonstration Program for the current fiscal year; temporarily extends Medicaid spousal-impoverishment protections; reduces the federal Medicaid matching rate for states that have not implemented asset-verification programs for determining Medicaid eligibility; reduces funding available to the Medicaid Improvement Fund beginning in FY2021.

Bipartisan Bill to Lower Rx Drug Prices

On July 23, Senate Finance Committee Chairman Charles Grassley (R-IA) and the committee’s Ranking Member, Ron Wyden (D-OR), [announced](#) that they had developed the *Prescription Drug Pricing Reduction Act (PDPRA) of 2019*, and that the bill would be considered (“marked up”) by the committee on July 25. See [Finance Committee Press Release](#), 7/23/19.) The bill would amend Parts B (outpatient) and D (drugs) of the Medicare program, and the Medicaid program. Among other things, the bill would amend the membership requirements and strengthen conflict-of-interest protections for the bodies that establish state Medicaid drug formularies and ensure availability of necessary drugs (Pharmacy and Therapeutics [P&T] Committees and Drug Use Review Boards). The bill would require that the physician and pharmacist members of P&T Committees be required to have expertise in the care of at least one Medicaid-specific beneficiary population, such as elderly or disabled, **children with complex needs**, or low-income chronic care individuals. The same standards would be required for the development of formularies by Medicaid managed care organizations. The bill would also permit states to pay over time for gene therapy. See a [detailed summary](#) of the bill (Medicaid provisions start on p. 28). See also [Senate Committee Unveils Ambitious Plan to Cap Drug Price Hikes, Out-of-Pocket Expenses](#) (STAT, 7/23/19); [Senate Finance Pushes Ahead on Plan To Address High Drug Prices](#) (Roll Call,

7/23/19). The bill is [supported](#) by some outside organizations, but [opposed](#) by the Pharmaceutical Research and Manufacturers of America (PhRMA). A House bill is expected to be unveiled in September. See [Pelosi Aide: Major Bill to Lower Drug Prices Coming in September](#) (The Hill, 7/22/19).

MEDICAID NEWS, INFORMATION, AND RESOURCES

[Understanding Medicaid Buy-in: A Tool to Advance Employment for People with Disabilities](#)

The Administration for Community Living, the Centers for Medicare & Medicaid Services (CMS), and the Department of Labor's Office of Disability Employment Policy (ODEP) have released a new "question and answer" document to help grantees, stakeholders, and self-advocates better understand the "Medicaid buy-in" program, through which states can allow workers with disabilities who are earning income to charge premiums for Medicaid coverage.

MEDICAID WAIVERS

[Patient/Consumer Groups Express Opposition to Waivers](#)

On July 18, 27 patient groups sent a [letter](#) to the Centers for Medicare and Medicaid Services (CMS) Administrator, Seema Verma, to express opposition to policies that would allow states to apply for block grants or per capita caps for their Medicaid programs.

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](#).

AFFORDABLE CARE ACT – NEWS, INFORMATION, AND RESOURCES

WORTH REPEATING:

- **Certified Application Counselor Designated Organizations - [Live Application Link now available](#). Deadline 9/16/19**

The Centers for Medicare & Medicaid Services (CMS) is inviting organizations that would like to become Certified Application Counselor Designated Organizations (CDOs) to apply during CMS's Open Season, which **ends September 16, 2019**. In the Federally-facilitated Marketplace, CDOs oversee certified application counselors (CACs) who are trained and able to help consumers seeking health coverage options through the Marketplace. **Any organization seeking to provide CAC enrollment assistance to consumers for Plan Year 2020 must be a certified CDO.** In order to be designated as a CDO, you must submit an online application and enter into an agreement with CMS. **If your organization completed the CDO refresh process last year and received a new CDO identification number and a welcome packet, then you do not need to reapply.** CDO Application technical assistance webinar recordings, user guides, and more can be found [here](#). The application itself can be found [here](#). For additional questions, contact CACQuestions@cms.hhs.gov. **NOTE** the webinar for potential CDO applicants listed in the "Upcoming Webinars" section above.

TRICARE

[FEDVIP Provides Vision Coverage to TRICARE Beneficiaries](#)

(July 23, 2019)

[Get to Know Your TRICARE Retired Reserve Plan](#)

(July 24, 2019)

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

[Trump Administration Moves to End Food Stamps for 3 Million People](#)

(Bloomberg, 7/23/19)

The administration has issued a [proposed rule](#) that would give states less flexibility to expand eligibility for food stamps. The Department of Agriculture estimates that the proposal would make 3.1 million people ineligible for the program. The proposal is open for [public comment](#) through September 23, 2019. See also [Trump Proposal Would Push 3 Million Americans Off Food Stamps](#) (Washington Post, 7/23/19).

RESOURCES:

From Other Organizations:

National Alliance on Mental Illness (NAMI):

[Say It Out Loud: Speaking with Teens about Mental Health](#) gives adults tools to talk with teens about mental health, with the aim of removing stigma associated with getting treatment. It resource be adapted for use by community-based organizations, faith-based organizations and schools.

WORTH REPEATING:

From the National Immigration Law Center:

[You Have Rights - Protect Your Health](#) – This document provides an overview for immigrant and mixed-status families of their rights when it comes to **going to the doctor** and **enrolling in health insurance**. (NILC has templates of this document available. If you are interested in a template to tailor and brand for your own organization, please reach out to Kat Lundie (lundie@nilc.org))

From *Clinical Pediatrics*:

[A Step-by-Step Guide to Building a Complex Care Coordination Program in a Small Setting](#). This report from *Clinical Pediatrics* describes a care support project that delivered shared plans of care to providers and families of children with medical complexity.

YOUR INPUT SOUGHT

Due August 12: [CMS Seeks Public Input on Patients over Paperwork Initiative to Further Reduce Administrative, Regulatory Burden to Lower Healthcare Costs](#)

(CMS Press Release, 6/6/19) This Request for Information solicits public comment on ideas for regulatory, subregulatory, policy, practice, and procedural changes that reduce unnecessary administrative burdens for clinicians, providers, **patients, and their families**.

Due August 13: Proposed Rule On Nondiscrimination In Health Care

In June, the Department of Health and Human Services (HHS) issued a [proposed rule](#) (Notice of Proposed Rulemaking) to revise regulations implementing Section 1557 of the Affordable Care Act (ACA) ([HHS Fact Sheet](#)). That ACA provision prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in any health program or activity that receives Federal financial assistance and certain other health programs or activities. Among the issues that the Notice of Proposed Rule Making seeks input on is, "whether HHS's Section 504 regulations at 45 CFR part 85 should be amended to address effective communication, accessibility standards for buildings of facilities, accessibility of electronic information technology, and the requirement to make reasonable modifications for otherwise qualified individuals with disabilities under any program or activity receiving Federal financial assistance from HHS." On July 1, the Kaiser Family Foundation issued a [summary and analysis of the proposed rule](#). Some analysts and advocates believe that, as written, the proposed rule would result in inadequate protections against discrimination for some of the protected populations. See [this article from the Health Affairs blog](#) (5/25/19); and [this article from the Commonwealth Fund](#) (6/12/19). Public comments on the proposed rule are due on August 13, 2019, and can be submitted [online via regulations.gov](#).

Due August 19: Debt Collection Practices

The Consumer Financial Protection Bureau (CFPB) has issued a [Notice of Proposed Rulemaking](#) (proposed rule) to implement the Fair Debt Collection Practices Act (FDCPA). (See the CFPB [press release](#).) The proposal would protect consumers against harassment by debt collectors and provide them with options to address or dispute debts, including medical debt. See [Mired In Medical Debt? Federal Plan Would Update Overdue-Bill Collection Methods](#) (Kaiser Health News, 5/31/19). Comments may be submitted via [Regulations.gov](#) and are due no later than 11:59 pm ET, August 19, 2019.

FDA Patient Representatives

Are you a patient or caregiver who wants to get involved at FDA? Contact [the Patient Affairs Staff \(PAS\)](#) or follow us on Twitter [@FDAPatientInfo](#).

SPECIAL ANNOUNCEMENT

StoryBooth: Opportunity to Share YOUR Health Care Story!

Do you have a story about your health care experiences you'd like to share? Family Voices is working with the University of Pittsburgh to help promote their StoryBooth project. This is a research project designed to collect stories from patients and families about their experiences with health care. The hope is that by listening to the stories of people they can improve health care for others. In addition to stories from adults (patients and caregivers), they would like to include some

stories from youth directly (must be at least 18 years old to participate). Stories are collected through phone interviews and then will be added to their [website](#). You can listen to some of the stories they've collected there. People who share their stories will be asked where they heard about the project, and then ask for permission to share the story with the source. Family Voices would love to be able to share your stories as well. Click on the links for two posters for general information and contact information:

- [General audience](#)
- [Youth audience](#)

OF POSSIBLE INTEREST

[High Fives and Sobs Greet UnitedHealthCare's Reversal Of Denials For Gene Therapy](#) (Washington Post, 7/18/19)

[How To Get A Cheaper Prescription before Leaving the Doctor's Office](#) (Kasier Health News, 7/10/19)

[Did Your Health Plan Deny You Care? Fight Back](#) (Kaiser Health News, 7/15/19)

[Caregiving For A Loved One? How to Get the Help You Need](#) (NPR, 7/14/19)

[How Much U.S. Households with Employer Insurance Spend on Premiums and Out-of-Pocket Costs: A State-by-State Look](#) (Commonwealth Fund Issue Brief, 5/23/19)

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

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U40MC00149. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by, HRSA, HHS, or the U.S. Government.