



FAMILY VOICES[®]

Washington DC Update
August 9, 2019

SPECIAL BULLETIN: The 5-year funding extension for Family-to-Family Health Information Centers is now law!

GREETINGS FROM WASHINGTON!

GREAT NEWS! The president has signed the bill that extends funding for Family-to-Family Health Information Centers (F2Fs) for five more years (through FY 2024) at the current funding level of \$6 million per year! The legislation also makes permanent the provision that requires the establishment of F2Fs for territories and tribes. Read more about this in “The Administration” section below.

In other news: After a long wait, the Administration for Community Living has announced the names of those appointed to serve on the RAISE Family Caregiving Advisory Council and has scheduled the Council’s first meeting. See the “Other News” section below for more,.

{Please note: There will be no Washington Update during the remainder of Congress’ August recess.}

REMINDER: Due on Tuesday, August 13, are public comments on the proposed rule on nondiscrimination in health care (implementing §1557 of the Affordable Care Act). The proposed regulations would alter the current standards for ensuring language access as well as protections from discrimination with respect to insurance decisions and the provision of health care services. See the “Your Input Sought” section below for more.

REMINDER: Meet with your Members of Congress during the August recess. Members of Congress are back at home in August. Their calendars get crowded quickly, so make an appointment now. You can [Find the local-office numbers for your Members of Congress](#), and [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). If you want to brush up on how a bill becomes a law, check out [The Essential Guide to Legislation](#) (from Politico Pro).

REMINDER: 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. **Deadline: 9/16/19.**

UPCOMING WEBINARS AND CALLS

NEW Marketplace updates

Friday, August 9, 2:00-3:00 pm ET

Centers for Medicare and Medicaid Services (CMS)

Topics: (1) a complex case scenario examining a pregnant consumer’s options for herself, her newborn, and her partner through pregnancy and postpartum care; (2) an overview of options for those who have experienced domestic violence or spousal abandonment and need to enroll in health care coverage apart from their abuser or abandoner.

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)

NEW From Coverage to Care (C2C): How to Successfully Navigate Health Coverage

Spanish: De la Cobertura al Cuidado de su Salud: cómo navegar con éxito la cobertura de salud

Wednesday, August 14, 2:00-3:00 pm ET

Centers for Medicare & Medicaid Services Office of Minority Health

Learn more about the C2C initiative and the resources available to help patients and caregivers understand their health coverage and connect to primary care, preventive, and behavioral health services.

NEW Using Peers to Support Re-Engaging Families

Thursday, August 15, 2:00-3:30 pm ET

Substance Abuse and Mental Health Services Administration (SAMHSA)

SERIES: #ABLEtoSave Awareness Campaign

An Orientation on What You Need to Know About ABLE

- **Thursday, August 15, 2:00-3:00 pm ET: ABLE Best Practices and Action Steps for Family Members and Supporters (Circle of Support)**
- **Thursday, August 22, 2:00-3:00 pm ET: ABLE Best Practices for Working-Age Adults**
- **Thursday, August 29, 2:00-3:00 pm ET: Celebrating All the Ways You are ABLE: Announcing Winners from #ABLEtoSave Video Contest and Next Steps!**

Critical Crossroads: Pediatric Mental Health Care in the Emergency Department

Thursday, August 15, 3:00-3:30 pm ET

Health Resources and Services Administration

This webinar will discuss a new toolkit to help prepare hospital emergency departments to manage care for children and adolescents in mental health crisis.

Family Voices, Inc. • Mailing Address: P.O. Box 37188, Albuquerque, NM 87176 • Physical Address: 3701 San Mateo Blvd NE, Suite 103, Albuquerque, NM 87110 • Phone: 505-872-4774 • Toll Free: 888-835-5669 • Fax: 505-872-4780 • Website: www.familyvoices.org

Moving the Needle on Health Equity: Two Experts Share Successful Programs and Lessons Learned

Wednesday, August 21, 1:00-2:00 pm ET

National Institute for Children's Health Quality

Person-Centered Planning and Practice

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

- **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

THE ADMINISTRATION

President Signs Bill to Extend Funding for F2Fs and Other Programs

On August 6, the president signed the [*Sustaining Excellence in Medicaid Act of 2019*](#) (H.R. 3253; Public Law 116-39). Among other things, the law provides funding for Family-to-Family Health Information Centers (F2Fs) for five more years – through FY 2024 – at the current funding level of \$6 million per year. The legislation also makes permanent the provision that requires the establishment of F2Fs for territories and tribes. This 5-year funding extension will help F2Fs more effectively and efficiently plan ahead, retain experienced staff, and expand partnerships in the community.

The F2F extension was added by the Senate to a House bill originally called the *Empowering Beneficiaries, Ensuring Access, and Strengthening Accountability Act of 2019*, to extend the Money-Follows-the-Person demonstration program, which helps people move from nursing homes into the community; impoverishment protections for spouses of individuals receiving Medicaid home- and community-based care; and the [*Certified Community Behavioral Health Clinic Demonstration Program*](#). The original bills to extend the F2F program (S. 1647 and H.R. 2822) were sponsored by Senators Chuck Grassley (R-IA) and Robert Menendez (D-NJ), and by Representatives Mikie Sherrill (D-NJ) and Fred Upton (R-MI).

For more information, see the [Family Voices website](#).

President Signs Budget Deal

On August 2, the president signed [*Bipartisan Budget Act of 2019*](#) (H.R. 3877). The law reflects a budget agreement between House Speaker Nancy Pelosi and Treasury Secretary Steve Mnuchin. It will increase both defense and non-defense “discretionary” (appropriated) spending for federal fiscal years 2020 and 2021, and suspend the nation’s debt ceiling until July 31, 2021, averting a default on the national debt until later that year. [*Trump Signs Massive Two-Year Budget Deal into Law*](#) (NBC News, 8/2/19). Congress must pass appropriations bills to provide funding for federal departments and agencies before the end of the federal fiscal year, September 30, 2019.

MEDICAID NEWS, INFORMATION, AND RESOURCES

CIB: Further Guidance on Implementation Electronic Visit Verification

From Medicaid Bulletin, 8/8/19:

The Centers for Medicare & Medicaid Services (CMS) continues to provide technical assistance to states and other stakeholders to ensure compliance with the 21st Century Cures Act. The Agency has received numerous requests from states and stakeholders to clarify certain electronic visit verification (EVV) requirements. Today CMS issued an Informational Bulletin (CIB) that includes a set of frequently asked questions to provide guidance regarding the applicability of EVV requirements to beneficiaries with live-in caregivers, the provision of durable medical equipment, and services rendered partially in the home and partially in the community, where requirement may create privacy concerns. This guidance also affirms that web-based electronic timesheets alone are not sufficient for ensuring EVV compliance.

- [EVV Resources Page](#)
- [CIB: Electronic Visit Verification](#)

New State Flexibilities and Requirements regarding Alternative Benefit Plans (ABP) and Essential Health Benefits (EHB)

From CMS Newsletter, 8/8/19:

Yesterday, CMS issued an [Informational Bulletin](#) to inform states about new flexibilities for defining essential health benefits (EHB) in Medicaid Alternative Benefit Plans (ABP) effective January 1, 2020. The bulletin explains three new options available to states when choosing the benchmark plans used to define EHB in its ABP. States with existing ABPs may continue to use the benchmark plan they currently use to define EHB for ABPs, but states selecting new benchmark plans to define EHB for ABPs are required to use one of the new options beginning on or after January 1, 2020. The bulletin also provides a reminder to states on state plan amendment (SPA) submissions and ABP public notice requirements.

[CIB: New State Flexibilities and Requirements regarding Alternative Benefit Plans \(ABP\) and Essential Health Benefits \(EHB\)](#)

New Guidance Encourages States to Better Address Children and Youth's Access to Mental and Behavioral Health Services

(Community Catalyst blog post, 7/17/19)

MEDICAID WAIVERS

1115 Waiver Demonstration - West Virginia Creating a Continuum of Care for Medicaid Enrollees with Substance Use Disorders

Medicaid Bulletin, 8/7/19

West Virginia is submitting a request to amend *Creating a Continuum of Care for Medicaid Enrollees with Substance Use Disorders* section 1115(a) demonstration. The goal of the amendment is to give the authority to allow the **Children with Serious Emotional Disorder 1915(c) demonstration** to be limited to a single specialized MCO. The federal public comment period will be open from August 7, 2019 through September 6, 2019.

- [Pending Application](#)
- [View/Submit Public Comments](#)

[With Trump's Blessing, Some States Aim to Cap Medicaid Rolls](#)

(Pew Stateline, 7/24/19)

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](#).

TRICARE

From TRICARE Benefits Updates:

- [Ditch the Ticks this Summer: Protect Your Family from Lyme Disease](#) (8/2/19)
- [Get Kids Ready for Back-to-School With Preventive Health Care](#) (8/6/19)
- [Start the School Year Right With Healthy Teeth](#) (8/8/19)

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

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

OTHER NEWS, INFORMATION, AND RESOURCES

NEWS:

[ACL Announces Initial Meetings of Caregiver Advisory Councils](#)

ACL Update, 8/7/19:

The Administration for Community Living is pleased to announce the first meetings of the advisory councils established by the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act and the Supporting Grandparents Raising Grandchildren (SGRG) Act.

Both meetings will be held on August 28 - 29 at the Holiday Inn—Washington Capitol, located at 550 C Street SW, Washington, DC 20024. The meetings will be open to the public (registration required) and will be live streamed.

A complete list of council members, as well as schedules and registration instructions for participating in the meetings, can be found at [ACL.gov/RAISE](#) and [ACL.gov/SGRG](#).

The [RAISE Family Caregiving Advisory Council](#) [scroll down on page to see list of Council members] is charged with providing recommendations on effective models of family caregiving and support to family caregivers, as well as improving coordination across federal government programs. These recommendations will support the development and execution of a national family caregiving strategy.

The [Advisory Council to Support Grandparents Raising Grandchildren](#) will identify, coordinate, and promote information, resources, and best practices available to help grandparents and other older

relatives meet the needs of the children in their care, while also maintaining their own physical, mental, and emotional well-being.

Each council is composed of members of the public selected based on demonstrated knowledge, qualifications, and professional or personal experience with the issues each council will address. In addition, each includes representatives from federal organizations that play a role in these issues

Trump Administration Makes CAR T-Cell Cancer Therapy Available to Medicare Beneficiaries Nationwide

(CMS Press Release, 8/7/19)

YOUR INPUT SOUGHT

NEW - Due August 30: The Help Me Grow National Center Parent Survey

The Help Me Grow National Center would like YOUR input—and input from families you work with. **Please share** the information and the links to the survey ([English](#) and [Spanish](#)) below. The survey takes about 7 minutes to complete (on average), and will be **open until COB Friday, August 30, 2019**. Here is information about the parent survey:

The purpose of this parent survey is to help us better understand your current experiences in taking your child for routine visits with his or her child health provider (or pediatrician).

As a parent/caregiver, you play an important role in understanding your child, his/her health and development, and areas where your family or your child may benefit from additional support. We are currently exploring possible ways to maximize your visit with the child health provider, such as by developing new questionnaires, visit planners, or by using technology to better support the visit. The results of this survey will allow us to understand what parents want/need in this area and directly inform future work.

Your individual response to the survey will not be shared. Thank you for taking the time to share your thoughts.

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 [this page on Regulations.gov](#) and are due no later than 11:59 pm ET, August 19, 2019.

Due Sept. 13: Proposed Rescission of Rule on Equal Access to Medicaid Services

On July 11, the Centers for Medicare and Medicaid Services (CMS) issued a [Notice of Proposed Rulemaking](#) to rescind the current regulations implementing the Medicaid law's "equal access" requirement, which requires that states "assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area." At the same time, the agency issued [an informational bulletin to state Medicaid officials](#) "to remind them of their ongoing statutory responsibilities to ensure appropriate access to care for beneficiaries," and to announce plans to develop alternative methods to monitor access. The current regulations, issued in 2015, govern only access to Medicaid services provided on a fee-for-service basis, as opposed to those provided under managed care arrangements, which are governed under other regulations. See the [CMS press release](#) for more details. Comments can be submitted through [this page on Regulations.gov](#).

Due September 23: Food Stamp Eligibility

The administration has issued a [proposed rule](#) that would restrict state 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. Comments may be submitted through September 23 via [this page on Regulations.gov](#). See also [Trump Proposal Would Push 3 Million Americans Off Food Stamps](#) (Washington Post, 7/23/19); [Trump Administration Moves to End Food Stamps for 3 Million People](#) (Bloomberg, 7/23/19).

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

[Pittsburgh Airport's 'Sensory Room' Supports Travelers Who Have Autism](#) (NPR, 8/8/19)

[The Washington Post: ICE Arrested Hundreds Of People In Raids. Now 'Devastated' Children Are Without Their Parents.](#) (Washington Post, 8/8/19)

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

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