



FAMILY VOICES[®]

Washington DC Update
June 21, 2019

GREETINGS FROM WASHINGTON!

The House has passed an appropriations bill that would provide a \$34 million increase in funding for the Title V Maternal and Child Health Block Grant in FY 2020. Key Senators have introduced a bill to address health care costs. The Kaiser Family Foundation has come out with two new issue briefs about children and youth with special health care needs and Medicaid. Read about these issues and more – and learn what a “manel” is – in this week’s Update. (And if you make it to the end, you can see some feel-good videos about ordinary young people spontaneously and sensitively responding to other young people with autism.)

APPLY TO BE AN ACA COUNSELOR or NAVIGATOR, or to get Navigator Funds:

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), **AND** the Centers for Medicare and Medicaid Services (CMS) has issued the Notice of Funding Opportunity (NOFO) for the Federally-facilitated Exchange (FFE) Navigator Program. See the ACA Section below for details.

UPCOMING WEBINARS AND CALLS

[Using Social Media to Build Rapport with Peers](#) [part of a [series](#)]

Tuesday, June 25, 2:00-3:00 pm ET

[Doors to WellBeing](#)

Intended for youth leaders and advocates doing peer mental health work.

[Promoting Access to Transportation Options with the National Aging and Disability Transportation Center](#)

Tuesday, June 25, 3:00-4:00 pm ET

National Information & Referral Support Center, National Aging and Disability Transportation Center

[How Can Medicaid and CHIP Support Children’s Emotional Health?](#)

Wednesday, June 26, 2:00-3:00 pm ET

Manatt Health, Center for the Study of Social Policy

Related resource: [Fostering Social and Emotional Health through Pediatric Primary Care: A Blueprint for Leveraging Medicaid and CHIP to Finance Change](#)

[Building Resilient Home Health Care with Energy Storage](#)

Thursday, June 27, 1:00-2:00 pm ET

Clean Energy Group (about battery-based back-up energy for medical equipment)

Related info: [Public Health Officials Call for Medicaid Coverage of Medical Battery Devices](#) (Fierce Healthcare, 6/5/19); [Home Health Care in the Dark](#) (report)

[Building Family Leadership and Voice](#)

Friday, July 12, 2:00-3:30 pm ET

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

[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 (NCAPPS)

[Pieces of the Same Puzzle: The Role of Culture in Person-Centered Thinking, Planning and Practice](#)

Tuesday, July 9, 3:00-4:30 pm ET

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

THE ADMINISTRATION

[NIH Director Will No Longer Participate in All-Male Panels](#)

(The Hill, 6/12/19):

“Francis Collins, director of the National Institutes of Health, on Wednesday said he will no longer participate in all-male panels - derisively referred to as ‘manels.’”

HHS Leadership Committed to Addressing Sickle Cell Disease

In a recent blog post, [Coming Together to Confront Sickle Cell Disease](#), Alex Azar, Secretary of the Department of Health and Human Services, and Adm. Brett P. Giroir, M.D., Assistant Secretary for Health, wrote: “[Sickle cell] disease is common enough in the United States that there are about 100,000 people currently living with SCD, but uncommon enough that medical professionals rarely see SCD patients. Only about 1 in 4 patients with SCD receive the standard of care described in current guidelines, and many studies have shown that patients do not receive treatment for their pain as soon as or in the appropriate doses as other patients. At HHS, we are committed to extending the lives of Americans with SCD by 10 years, within 10 years.”

CONGRESS

House Passes HHS Appropriations Bill with Increase for Title V

On June 19, the House of Representatives passed a package of four FY 2020 appropriations bills to fund the Departments of Labor, Health and Human Services (HHS), and Education (normally one bill); Defense; State; and Energy. The bill passed by a vote of 226 to 203, opposed by seven Democrats and all Republicans. It includes \$99.4 billion for HHS, an increase of \$8.9 billion above the 2019 level. See a

bill [summary](#) prepared by the House Appropriations Committee, and [House Backs \\$1T Spending Bill amid Fears of a Fall Shutdown](#) (Politico, 6/19/19). Included in the House bill is a significant increase for the Title V Maternal and Child Health Block Grant. As reported out of committee, the bill included an increase of \$27 million over the current (FY 2019) funding level for Title V. On the House Floor, Rep. Cedric Richmond (D-LA) offered an amendment to increase Title V funding by an addition \$7 million, which passed by a vote of 365-59. Thus, as passed by the House, the total amount for Title V is \$712 million, a \$34 million increase over current funding. The Senate Appropriations Committee may begin consideration of its version of the HHS spending bill after the July 4th recess. It is expected that the Senate committee will report out lower appropriations levels than are in the House bill.

Meanwhile, ultimate enactment of any appropriations bills is impeded by the “spending caps” that were set in the Budget Control Act of 2011. These caps have been raised temporarily multiple times since enactment of that law – via budget negotiations between administrations and Congress - in order to avoid government-wide automatic funding cuts (“sequestration”). The White House and congressional leaders are in the midst of negotiations as of this writing. See [Congressional Leaders, White House Officials Fail To Reach Budget Deal](#) (The Hill, 6/19/19).

House Passes Bill to Reauthorize Money Follows the Person Program

On June 18, the House passed the *Empowering Beneficiaries, Ensuring Access, and Strengthening Accountability Act* ([H.R. 3253](#)) by a vote of 371-46. Among other things, the bill will extend, through FY 2024, the Medicaid “Money Follows the Person” program, which helps people transition from institutional to community-based settings.

Tuesday Hearing on Legislation of Interest

On Tuesday, June 25, at 10:00 am ET, the Health Subcommittee of the Committee on Energy and Commerce will hold a legislative [hearing](#), “Reauthorizing Vital Health Programs for American Families,” which should be streamed live on the [committee website](#). The bills to be addressed are:

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

Senate Health Committee Leaders Introduce Bipartisan Legislation to Reduce Health Care Costs

(HELP Committee press release, 6/19/19)

On June 19, Senators Lamar Alexander (R-TN) and Patty Murray (D-WA) – respectively, Chairman and Ranking Member of the Committee on Health Education, Labor & Pensions (HELP) - introduced the *Lower Health Care Costs Act of 2019* ([S.1895](#)). They announced that the committee will vote on the legislation on June 26. The bill would address a number of issues relating to health care costs, including “surprise medical bills” and prescription drug prices, and public health, including maternal health and obesity. Read the bill [text](#) and [section-by-section summary](#). See [Key Senators Release Bipartisan Package to Lower Health Care Costs](#) (The Hill, 6/19/19). See also [Senators Agree Surprise Medical Bills Must Go. But How?](#) (Kaiser Health News, 6/18/19)

Bills Introduced to Protect and Assist Vulnerable Populations in Disasters

Two bills intended to ensure the safety of vulnerable populations during natural disasters have been introduced in both the House and Senate. The *Disaster Relief Medicaid Act* (DRMA) ([S. 1754](#), [H.R. 3215](#)) would ensure that Medicaid beneficiaries who are forced to relocate to another state due to a disaster can continue to access their Medicaid-supported services, and would provide resources for states experiencing an influx of disaster survivors. The *Real Emergency Access for Aging and Disability Inclusion for Disasters* (READI) Act ([S. 1755](#); [H.R. 3208](#)) would help to ensure that people with disabilities and older adults are included and considered in disaster preparation and response by, among other measures, establishing a National Commission on Disability Rights and Disasters to make recommendations for best practices, and creating a network of centers to assist states and localities create inclusive disaster plans. Should the READI bill be enacted, Family Voices will work to ensure that families of CYSHCN are included on the Commission. Learn more about both bills at <https://reaadi.com>. For more about the topic in general, check out [The Partnership for Inclusive Disaster Strategies](#).

F2F Funding

As reported in the [June 13 Update](#) and other recent Updates, bipartisan House and Senate bills have been introduced to extend funding for Family-to-Family Health Information Centers (F2Fs) for an additional five years, through federal FY 2024, at the current level of \$6 million per year. More details on these bills and the June 4 hearing on the House bill can be found on the [Family Voices website](#). On June 11, Senator Bernie Sanders (I-VT), along with seven other Democratic Senators, introduced the *Territories Health Equity Act of 2019* ([S.1773](#)), which includes numerous Medicare, Medicaid, and other provisions related to health care in the territories. Among these is a provision that would permanently extend funding for the F2F program at the current level of \$6 million per year. The House version of the bill ([H.R. 1354](#)), which was introduced by Rep. Stacey Plaskett (D-US Virgin Islands) in February, includes an identical provision. Significantly, none of the current sponsors of either the House or Senate versions of the territorial health bills serves on a committee to which the bills have been referred. For this and other reasons, it is unlikely that we could secure a permanent F2F funding extension or an extension any longer than that of the other “health extenders” that typically travel together in one package of legislation.

MEDICAID NEWS,

INFORMATION, AND RESOURCES

[Medicaid Financial Eligibility for Seniors and People with Disabilities: Findings from a 50-State Survey](#)

(Kaiser Family Foundation Issue Brief, 6/14/19)

[How Do Medicaid/CHIP Children with Special Health Care Needs Differ from Those with Private Insurance?](#)

(Kaiser Family Foundation Issue Brief, 6/12/19)

[Medicaid’s Role for Children with Special Health Care Needs: A Look at Eligibility, Services, and Spending](#)

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

(Kaiser Family Foundation Issue Brief, 6/12/19)

Public Health Officials Call for Medicaid Coverage of Medical Battery Devices

(Fierce Healthcare, 6/5/19) Report: [Home Health Care in the Dark](#)

MEDICAID WAIVERS

Blog post: [New Medicaid Waiver Policies Can Lead to Loss of Needed Coverage](#) (AARP Thinking Policy blog, 6/4/19 – good overview of Medicaid waivers and concerns they raise)

Report: [The New Medicaid Waivers: Coverage Losses for Beneficiaries, Higher Costs for States](#) (AARP Public Policy Institute, June 2019)

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

Certified Designated Organizations - [Live Application Link](#) now available.

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.

Notice of Funding Opportunity for Navigator Grants. [To view the Notice of Funding Opportunity (NOFO), please visit: <http://www.grants.gov>, and search for CFDA # 93.332.]

The Centers for Medicare and Medicaid Services (CMS) issued a Notice of Funding Opportunity (NOFO) for the Federally-facilitated Exchange (FFE) Navigator Program, which funds Navigator Organizations to provide in-person, enrollment assistance for individuals seeking health coverage. The NOFO announces the same \$10 million annual level of funding as last year. The announcement also expands the period of performance from one year to two years in order to promote stability in the program and improve the consumer experience. The total available funding for the first 12-month budget period will be allocated among the 34 FFE states based on the size of the remaining, eligible uninsured population in each FFE state. A minimum of \$100,000 will be available to each eligible state. Changes in the 2020 Payment Notice also created new flexibility for the Navigator Program. Certain types of assistance,

including post-enrollment duties, for FFE Navigators are now permissible, but not required. This change will provide grantees with more flexibility and allow them to allocate their grant funding based on the unique needs of their community. As required in previous years, under the Terms and Conditions of cooperative agreements awarded under this NOFO, funding for the second 12-month budget period will be contingent on the awardee continuing to meet all Navigator program requirements, current program priorities, and the availability of funds. To view the Notice of Funding Opportunity (NOFO), please visit: <http://www.grants.gov>, and search for CFDA # 93.332.

TRICARE

From recent TRICARE Benefits Updates:

[TRICARE Extended Care Health Option Helps Families with Special Needs](#)

(6/13/19)

The TRICARE Extended Care Health Option (ECHO) provides supplemental health care coverage for active-duty family members with a qualifying mental or physical disability.

- *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

Executive Order to Reduce the Number of Federal Advisory Committees

On June 14, the president issued an [Executive Order](#) directing every department and agency to cut by at least one-third the number of advisory committees under its purview, except those required by law, by September 30, 2019. The Order also limits the total number of advisory committees to 350 government-wide, excepting those required by law. If that limit is exceeded, then an agency may not establish a new advisory committee unless it receives a waiver. According to the June 18 newsletter of the National Conference of State Legislatures, citing the General Services Administration, there are currently more than 1,000 active advisory committees, 601 of which are required by various statutes.

New National Center on Advancing Person-Centered Practices and Systems

The Administration for Community Living (ACL) and the Centers for Medicare & Medicaid Services (CMS) have launched a new initiative - the [National Center on Advancing Person-Centered Practices and Systems](#) (NCAPPS) - to help States, Tribes, and Territories implement person-centered practices.

RESOURCES:

From the CDC:

[Essentials for Parenting](#)

From Our Partners:

ABLE Account Information

The [ABLE National Resource Center](#) has developed a [fact sheet and comparison chart](#) about three types of protected savings accounts that make it possible for individuals to accumulate savings and still maintain eligibility for benefits such as Medicaid, SSI and the Supplemental Nutrition Assistance Program (SNAP). The fact sheet provides basic information on three options for establishing protected savings accounts: ABLE, Pooled Trust and Special Needs Trust (first and third party). The chart that follows contains a comparison tool to help determine which option(s) best meet the needs of an individual. Also available from the ABLE National Resource Center: [Top 3 ABLE Questions, June 2019](#)

WORTH REPEATING: [Preparing for the Transition from Pediatric to Adult Health Care: Parent Guide](#) (PDF) – from *Got Transition*

YOUR INPUT SOUGHT

Due June 21, 11:59 pm ET. Federal Inflation Measures for Poverty Thresholds

New resource: [Changes to Poverty Measure Could Disqualify Thousands from State and Federal Programs](#) (National Academy for State Health Policy Blog, 6/17/19)

On May 7, the Office of Management and Budget (OMB) – part of the White House – issued a “[Notice of Solicitation of Comments](#)” about what consumer price index should be used to establish the “Official Poverty Measure,” which serves as the basis for poverty guidelines used to determine income-based eligibility for programs such as Medicaid and CHIP. Should OMB ultimately adopt a different inflation index, it could reduce the number of people eligible for these programs, and these reductions would become greater over time. See [White House Wants to Update Poverty Thresholds. It Could Affect Food Stamps and Medicaid Benefits](#) (Roll Call, 5/13/19), and [this blog post from the Georgetown University Center on Children and Families](#), which explains the issues involved. Comments are due on June 21 (11:59 pm ET), and can be submitted via [Regulations.gov](#).

Due June 21. HHS/Office of Intergovernmental and External Affairs: Call for

nominations to serve on the [Secretary's Tribal Advisory Committee \(STAC\)](#). The committee seeks primary delegates and alternates for Albuquerque, NM and Billings, MT, as well as three (3) National At-Large Primary Delegates and one (1) National At-Large Alternate Delegate. All nominees must either be elected or appointed Tribal officials acting in their official capacity as elected officials of their Tribes. For further information, please contact [Stacey Ecoffey](#).

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 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.

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

[Compassion Fatigue Hits Not Only Professional Caregivers. Other People Get It, Too.](#) (Washington Post, 6/9/18)

[A 21st Century Job Description for Family Caregiving](#) (Health Affairs blog, 6/14/19)

[‘The American Healthcare System Has Just, Quite Literally, Ruined My Future,’ A Disabled Georgetown Student Tweeted. Then She Got a Reprieve.](#) (Washington Post, 6/15/19)

[As Price of Insulin Soars, Americans Caravan to Canada for Lifesaving Medicine](#) (Washington Post, 6/16/19)

[Leadership Program Helps Health Advocates Connect More Kids and Families to Medicaid](#) (Annie E. Casey Foundation, 5/31/19)

About Vaccines (NOTE: The NY Times limits the number of free articles per month):

- [By the Numbers: Vaccines Are Safe](#) (NY Times, 6/18/19)
- [Vaccine Injury Claims Are Few and Far Between](#) (NY Times, 6/18/19)
- [One More Time, With Big Data: Measles Vaccine Doesn't Cause Autism](#) (NY Times, 3/5/19)

FEEL GOOD:

- [Teen Praised for Going 'Above and Beyond' to Help Little Girl With Autism Experiencing Sensory Overload](#) (Good News Network, 6/2/19)
- [Employee Lets Autistic Teen Stock the Shelves; Video Goes Viral and Strangers Give Him \\$120K](#) (Good News Network, 5/7/19)

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.