



FAMILY VOICES[®]

Washington DC Update
March 29, 2018

GREETINGS FROM WASHINGTON!

It's been barely a week since the president signed a bill to provide final spending levels for the current fiscal year (which began last October). The law provides spending increases for a number of health-related programs, including the Title VI Maternal and Child Health Block Grant, respite care, and developmental disabilities programs. Get the details in this week's Update, along with information about TRICARE's policy on medical foods, and other resources.

**** Spring holiday. Congress is in the first week of a two-week recess, so there will be no Washington Update for the following two weeks. Happy Passover, Easter, and other spring celebrations! ****

UPCOMING WEBINARS AND CALLS (ALL TOPICS)

NEW Unpacking the Bipartisan Budget Act: What are New Opportunities for Kids' Health and Prevention

Thursday, March 29, 1:00 ET

Georgetown Center on Children and Families

Understanding Your TRICARE Preventive Care Benefits

Thursday, March 29, 1:00-2:00 ET

Military OneSource

[Related article](#)

How to Improve Air Travel for Wheelchair Users

Thursday, March 29, 3:00-4:00 ET

United Spinal Association

NEW Marketplace Assister Webinars

Friday, March 30, 2:00-3:30 ET

Centers for Medicare and Medicaid Services (CMS)

(1) How to obtain and handle consumers' personally identifiable information (PII).

Related resources:

- How to Obtain a Consumer's Authorization before Gaining Access to PII, available [here](#)
- Requirements and Best Practices for Assisters on Handling PII, available [here](#)
- Model Authorization Forms for Navigators in [English](#) and [Spanish](#)
- Model Authorization Forms for certified application counselors in [English](#) and [Spanish](#)

(2) Stand-Alone Dental Plans (SADPs)

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

[Accessibility Issues in Rail Transportation](#)

Tuesday, April 3, 2:00-3:30 ET

TransCen, Inc. and the Mid-Atlantic ADA Center

[Webinar Series for Youth Self-Advocates: Leadership is a Journey](#)

Sponsored by NCFPP, Autistic Self-Advocacy Network, KASA, and Youth MOVE.

Knowing Yourself as a Change Agents

Part One: Leadership Styles

Wednesday, April 4, 6:00-6:30pm ET

Part Two: Self-Assessments & Reflection

Wednesday, April 18, 6:00-6:30pm ET

What is My Culture? What are My Values?

Part One: Culture and Values Reflection

Wednesday, May 2, 6:00-6:30pm ET

Part Two: The Role of Youth Leadership within Health Equity Work

Wednesday, May 16, 6:00-6:30pm ET

Cultural Perspectives on Self-Care in Leadership

Wednesday, May 30, 6:00-6:30pm ET

[A Conversation on the Emergence of Pediatric Complex Care](#)

Tuesday, April 10, 1:00-2:00 ET

Lucile Packard Foundation for Children's Health

[Caregivers: Learn to Listen to Yourself and Cultivate Beneficial Self-Care Habits](#)

Wednesday, April 11, 3:30 ET

Triage Cancer

[NEW Providing Culturally Competent Care: Meeting the LTSS Needs Of Dually Eligible Beneficiaries](#)

Thursday, April 12, 12:00-1:30 ET

Resources for Integrated Care

[NEW From Coverage to Care – All about the Office of Minority Health](#)

Thursday, April 12, 1:00-2:30 ET

Centers for Medicare and Medicaid Services (CMS)

[NEW Cultural and Linguistic Competence Peer Learning Exchange – Cultural and Behavioral Health Equity Considerations for Wraparound Practice](#)

Thursday, April 12, 2:30-3:30 ET

Substance Abuse and Mental Health Services Administration (SAMHSA)

[NEW Rare Disease Caregiving in America](#)

Wednesday, April 18, 4:00 ET

The National Alliance for Caregiving and Global Genes

The webinar will discuss the recently released report **[Rare Disease Caregiving in America](#)**.

[Got Transition Webinar Series -- Health Care Transition for Title V Care Coordinators](#)

Got Transition/Center for Health Care Transition Improvement

- Integration into Adult Care (Thursday, May 31st, 3:00-4:00 ET);
- Youth, Young Adult, & Parent Engagement (Thursday, June 28th, 3:00-4:00 ET)

THE ADMINISTRATION

New CDC Director to be Appointed

On March 21, the Department of Health and Human Services [announced](#) that Secretary Alex Azar will name Robert R. Redfield, M.D., to be the new Director of the Centers for Disease Control and Prevention and the Administrator of the Agency for Toxic Substances and Disease Registry. Dr. Redfield currently serves on the faculty of the University of Maryland and is an expert in HIV/AIDS.

CONGRESS

It's been just over a week since Washington started holding its collective breath to see if both houses of Congress would pass, and the president would sign, the spending bill that had been negotiated for weeks by House and Senate leaders from both parties. The 2,232-page "omnibus" appropriations bill was unveiled on Wednesday evening, March 21. The House approved the bill at about 1:00 Thursday afternoon (by a vote of 256-167) and the Senate did so almost 12 hours later (by a vote of 65-32). Despite previous White House assurances that the president would sign the bill, [he created a bit of suspense](#) by [tweeting](#) early Friday morning that he might decide to veto the bill because it did not include any measures for [DACA recipients](#) or funding for a border wall. The city finally exhaled when President Trump signed the legislation Friday afternoon, averting a partial government shut-down that would have occurred at midnight.

The omnibus spending measure ([Public Law No. 115-141](#)) sets federal spending levels for appropriated government programs for **FY 2018**, which started last October 1. (More below.) A number of policy provisions were also at issue as the bill was negotiated.

Although the issue was discussed at length, in the end, the bill **did not** include any measures to stabilize the individual insurance market (due to disagreement about an abortion provision).

The bill **does** include provisions to address:

- [Wandering](#) by people with developmental disabilities or dementia -- "Kevin and Avonte's Law" ([S. 2070](#)), which provides grants to develop locally based programs to prevent wandering, locate missing individuals, and develop tracking technology programs to locate missing individuals with dementia or children with developmental disabilities.
- [Seclusion and restraint](#) practices in schools -- A requirement that the Government Accountability Office (GAO) conduct a study on data reported to the Department of Education's Office for Civil Rights about the use of seclusion and restraints and efforts to reduce the use of these practices; the report must also include GAO recommendations on effective alternatives to seclusion and restraint to reduce their use.

- School safety -- The bipartisan “Fix NICS” bill, to improve the background check system for gun purchases, and the bipartisan “STOP School Violence bill,” to establish a grant program to fund training on the signs of gun violence and to fund other measures to improve school security. The new law also includes the “Dickey amendment,” which prohibits the use of federal funds “to advocate or promote gun control,” but the explanatory report language says: “While appropriations language prohibits the CDC and other agencies from using appropriated funding to advocate or promote gun control, the Secretary of Health and Human Services has stated the CDC has the authority to conduct research on the causes of gun violence.” See [Republicans agree to clarify that CDC can research gun violence](#) (The Hill, 3/21/18).
- Child safety – The Child Protection Improvement Act, to establish a national criminal history background check system and criminal history review program for organizations that serve children, the elderly, and individuals with disabilities.

Pursuant to the overall discretionary (appropriated) spending levels agreed to in the Bipartisan Budget Act of 2018, enacted in February, the new law provides increases for many “non-defense discretionary” programs, including increases in a number of health- and disability-related programs. Some examples:

In the Health Resources and Services Administration (HRSA):

- MCH Block Grant – increased from \$641.7 to \$651.7 million (+1.55%)
- Autism and Other Developmental Disorders – from \$47.099 to 49.099 million (+4.2%)
- Emergency Medical Services for Children -- \$20.162 to \$22.334 million (+11%)

In the Administration for Community Living:

- Lifespan Respite Care Act – from \$3.36 to \$ 4.11 million (+22.3%)
- National Family Caregiver Support Program – from \$150.59 to \$180.586 (+19.9%)
- University Centers for Excellence in Developmental Disabilities (UCEDDs) –from 38.0 to \$40,619,000 million (+5.2%)
- Leadership Education in Neurodevelopmental and Related Disabilities (LENDs) -- from \$31.317 to \$32 million (+2.0%)

In the CDC:

- National Center on Birth Defects and Developmental Disabilities – from \$137.56 to \$140.56 million (+2.2%)

For more programs, see a [table prepared by The Arc](#).

[Note: Since the Family-to-Family Health Information Centers program is funded directly, rather than through appropriations legislation, its funding was provided in February’s Bipartisan Budget Act. The program received an increase in funding from \$5 to \$6 million (+20%), some of which will fund new grants for territories and tribes.]

Right-to-Try Legislation

On March 21, the House of Representatives approved (by a vote of 267-149) The Trickett Wendler, Frank Mongiello, Jordan McLinn, and Matthew Bellina [Right to Try Act of 2018](#) (H.R.5247), sponsored by Rep. Ryan Fitzpatrick (R-PA) and cosponsored by 44 other House Republicans. The bill would let terminally ill patients try medications that have not been approved by the Food and Drug Administration (FDA) through procedures outside of the FDA’s existing “compassionate use” process.

Citing concerns about patient safety, the bill is [opposed by many patient groups](#) and [four former heads](#) of the Food and Drug Administration (FDA) from the Obama and G. W. Bush administrations. The House-passed bill has been transmitted to the Senate for its consideration. (The Senate passed a different version of right-to-try legislation last August.)

MEDICAID NEWS, INFORMATION AND RESOURCES

Proposed Regulation on State Requirements to Assess Medicaid Access to Care

On March 22, The Centers for Medicare and Medicaid Services (CMS) issued a [proposed regulation](#) to reduce state regulatory burdens by exempting states with high rates of comprehensive Medicaid managed care from analyzing data and monitoring access in **fee-for-service** delivery systems. The rule would also exempt all states from undertaking this analysis when they make nominal rate reductions to fee-for-service payment rates. A [CMS press release](#) summarizes the proposals:

- States with an overall Medicaid managed care penetration rate of 85% or greater (currently, 17 States) would be exempt from most access monitoring requirements.
- Reductions to provider payments of less than 4% percent in overall service category spending during a State fiscal year (and 6% over two consecutive years) would not be subject to the specific access analysis..
- When states reduce Medicaid payment rates, they would rely on baseline information regarding access under current payment rates, rather than be required to predict the effects of rate reductions on access to care, which states have found very difficult to do.

For more information on current regulations regarding Medicaid access to care, click [here](#). Comments on the proposed rule are due on **May 22** and can be submitted [here](#).

TRICARE

[TRICARE Coverage for Medically Necessary Nutritional Needs](#)

Recent changes to TRICARE benefits include updating the coverage for medically necessary foods and vitamins, and helping people with obesity get care to help manage their weight.

[Which Plan is Right for You? Comparing TRICARE Prime and TRICARE Select](#)

Those with TRICARE coverage can choose from a variety of plans, providing different options as to where and how one seeks medical and dental services. Two major health programs include TRICARE Prime and TRICARE Select.

OTHER NEWS, INFORMATION AND RESOURCES

From the Food and Drug Administration:

News: [FDA Authorizes First Fully Interoperable Continuous Glucose Monitoring System, Streamlines Review Pathway for Similar Devices](#)

Resource: [FDA In Brief: FDA Launches Mobile App to Increase Access to Information about Drugs](#)

From the CDC – for Families:

Checklist for Caregivers to Assist in Communicating with Health Care Providers

The CDC's National Center for Chronic Disease Prevention and Health Promotion has developed an easy-to-follow checklist, in an infographic, to assist caregivers in communicating with their care recipients' health care providers. [Webpage](#) – [can be added to your website](#); [PDF version](#) (to print).

From the ARCH National Respite Network and Resource Center – for Families:

During Developmental Disabilities Awareness Month, ARCH is pleased to release the second fact sheet in the series "[9 Steps to Respite Care](#)". This fact sheet includes resources for family caregivers of children and adults with intellectual and developmental disabilities (I/DD).

YOUR INPUT SOUGHT

[New postings are listed first, even if comments are due later than older postings.]

NEW SSA Seeks Input on Representative Payee Determinations for Beneficiaries

Comments due April 6

The Social Security Administration (SSA) [Representative Payee](#) Program provides financial management for Social Security and Supplemental Security Income (SSI) beneficiaries who are incapable of managing their Social Security or SSI payments. As part of its April 18 [National Disability Forum](#), the SSA is seeking public input on ways to improve its instructions for the Representative Payment Program -- specifically, how SSA can identify beneficiaries who can direct the management of their own benefits. Specific questions from SSA can be found, and feedback can be submitted [here](#). (Look for the black "Submit New Idea" box near the top right corner of the page.) Comments are due on **Friday, April 6, 2018**. Questions can be directed to Joie.Hill@ssa.gov.

NEW Request for Stakeholder Input on Dual Eligible Special Needs Plans (D-SNP)

Comments due April 12.

The [Bipartisan Budget Act of 2018](#) created a new Section 1859(f)(8) of the Social Security Act to increase integration of Dual Eligible Special Needs Plans (D-SNPs). The statute directs CMS to (1) develop unified grievance and appeals processes for D-SNPs; and (2) establish new standards for integration of Medicare and Medicaid benefits for D-SNPs. The CMS Medicare-Medicaid Coordination Office is soliciting comments to help inform its implementation of this provision from stakeholders working to address the needs of dual eligibles (individuals who are served by both Medicaid and Medicare). See the request for stakeholder input [here](#), which provides additional background information and outlines topics and questions on which input is sought. Please submit comments, using the subject line "**Comments on Section 50311,**" to MMCOCapsmodel@cms.hhs.gov no later than **April 12, 2018**.

NEW Proposed Regulation on State Requirements to Assess Medicaid Access to Care (see "Medicaid" section above)

Comments due May 22

Research Project on Perception of Caregivers

Comments due March 2018

When people hear that you are a caregiver, what do they tell you? This project will explore how people in the general population view caregivers through a 10-minute survey. The research is being conducted as part of a Dissertation Research project in the Department of Psychology and Neuroscience at the University of North Carolina, Chapel Hill. The study seeks to recruit 2,000 caregivers by March 2018. Learn more and participate [here](#).

Family-to-Family Health Information Center Feedback Survey

Comments due April 23

On February 21, 2018, the Health Resources and Services Administration (HRSA) published a [Notice](#) in the Federal Register requesting public comment on the new Family-to-Family Health Information Center (F2F) Feedback Surveys. As described in the Notice, HRSA has developed feedback surveys to determine the extent to which F2F HICs provide service to families of CYSHCN and health professionals who serve such families. This Notice was published pursuant to the requirements of the Paperwork Reduction Act of 1995, which requires agencies to estimate the paperwork burden associated with its collection of information.

HRSA specifically requests comments on:

- (1) The necessity and utility of the proposed information collection for the proper performance of the agency's functions
- (2) The accuracy of the estimated burden of completing the survey
- (3) Ways to enhance the quality, utility, and clarity of the information to be collected
- (4) The use of automated collection techniques or other forms of information technology to minimize the information collection burden.

The Notice does not include the actual survey on which comments are being solicited. Directions for obtaining the survey and submitting comments can be found in the Notice. Family Voices will get a copy of the survey, distribute it to the F2Fs, and compile comments from F2Fs that wish to provide them. Anyone can submit individual comments as well.

Proposed Rule on Short-Term, Limited-Duration Health Plans

Comments due April 23

See ACA section in the [2/28/18 Washington Update](#) for more information. Comments can be submitted [here](#).

State Legislators and Advocates Needed for Interviews

The [National Research Center for Parents with Disabilities and Their Families](#) is conducting interviews with individuals who have worked on state legislation to protect the rights of parents with disabilities and their children. Qualified participants must speak English, be 18 years or older, and have been involved with state legislation related to parents with disabilities as a legislator, legislative staff, advocate, attorney, or child welfare professional. Participants involved in pending legislation may also qualify. Information gathered from these interviews will be used to develop technical resources for advocates and legislators. For more information or to participate in an interview, contact Robyn Powell, JD, at rpowell@brandeis.edu.

We 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!

And, as always, please feel free to contact us with any questions. Comments and questions can be directed to jguerney@familyvoices.org.

Yours truly,
Janis Guerney
Family Voices Policy Director

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.