



# FAMILY VOICES<sup>®</sup>

Washington DC Update  
May 31, 2018

## GREETINGS FROM WASHINGTON!

The Department of Transportation is seeking comments on policies governing service animals in air travel. ♥ The Senate Finance Committee announced the introduction of 22 bipartisan bills to address the opioid crisis. ♥ The Health Equity and Accountability Act was introduced in the House. ♥ The Washington Post published an interesting interview with Seema Verma, the administrator of the Centers for Medicare and Medicaid Services (CMS). (See the Medicaid Waivers section below.) ♥ The Congressional Budget Office has projected increases in insurance premiums over the next decade. ♥ The FDA has determined that popular products for teething pain are unsafe (immediately below). Read about these issues and more in this week's Update.

*Congress is in recess this week, so there will be no Washington Update next week.*

**IMPORTANT FDA SAFETY ANNOUNCEMENT about TEETHING-PAIN PRODUCTS:** The U.S. Food and Drug Administration (FDA) is warning that over-the-counter (OTC) [oral drug products containing benzocaine should not be used to treat infants and children younger than 2 years of age](#) because they could cause a potentially life-threatening condition in which the amount of oxygen carried through the blood is greatly reduced. **The products that should not be used are gels, sprays, ointments, solutions and lozenges under the brand names Anbesol, Baby Orajel, Cepacol, Chloraseptic, Hurricaine, Orabase, Orajel and Topex, as well as store brands and generics.** The FDA is asking companies to stop marketing these drugs for use in infants and young children and to include a warning label on the products marketed to older individuals. Infants and young children also [should not be given certain homeopathic remedies](#) for teething pain. For more information see [the FDA Safety Announcement](#). Information for parents: [Do Teething Babies Need Medicine on Their Gums? No](#).

## UPCOMING WEBINARS AND CALLS

(All topics; in chronological order, by first webinar in a series where applicable.)

### [Developmental Screenings in Medicaid and CHIP: Federal Progress, State Opportunities](#)

**Thursday, May 31, 3:00 ET**

*Georgetown Center for Children and Families*

Related resources:

- [What do we know about developmental screenings in Medicaid and CHIP?](#) (blog)
- [Developmental Screenings for Young Children in Medicaid and CHIP](#) (brief)

### **Got Transition Webinar Series -- Health Care Transition for Title V Care Coordinators**

*Got Transition/Center for Health Care Transition Improvement*

- **Thursday, May 31st, 3:00-4:00 ET:** Integration into Adult Care
- **Thursday, June 28th, 3:00-4:00 ET:** Youth, Young Adult, & Parent Engagement
- *Thursday, April 26th, 3:00-4:00 ET: Transfer to Adult Care (already took place)*

### **A Guided Tour of the National Resource Center for Supported Decision-Making (NRC-SDM) Website**

**Monday, June 4, 3:00-4:00 ET**

*Family Voices, in partnership with Parent to Parent, USA, and Quality Trust*

For family leaders and family organization staff.

### **NEW The Psychology of a Crisis**

**Tuesday, June 5, 2:00-3:00 ET**

*Centers for Disease Control and Prevention (CDC)*

### **New Medicare Card Webinar for Medicare Beneficiaries**

**Tuesday, June 5, 2:30-3:30 ET**

*Centers for Medicare and Medicaid Services (CMS)*

### **A Conversation on Meaningful Family Engagement, from Clinical Care to Health Policy**

**Wednesday, June 6, 1:00-2:00 ET**

*Lucile Packard Foundation for Children's Health*

### **Connecting Students to Coverage This Back-to-School Season**

**Wednesday, June 6, 2:00-3:00 ET**

*InsureKidsNow.gov*

### **NEW Educational Advocacy after Brain Surgery, Part 2**

**Wednesday, June 6, 3:00-4:00 ET**

*Family Voices of California*

### **Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) Meeting**

**Friday, June 8, 9:00-5:00 ET; public comments 1:00-2:00 ET**

*Substance Abuse and Mental Health Services Administration (SAMHSA)*

Members of the public can attend the open, public portion of the meeting via telephone or webcast.

The meeting can be accessed via webcast on the [HHS Live Stream channel](#) on June 8. To join by telephone, **call 888-928-9713 and enter passcode 7160920**. The public comment section is scheduled for 1–2 pm Eastern Time. Individuals interested in submitting a comment must notify the Designated Federal Official, Ms. Pamela Foote, on or before May 24, 2018, via email at [Pamela.Foote@samhsa.hhs.gov](mailto:Pamela.Foote@samhsa.hhs.gov). [Although the deadline has passed, you can email Ms. Foote to see if it is possible to speak.] For more information, visit [SAMHSA's ISMICC webpage](#). If you have questions or to request special accommodations for persons with disabilities, contact [ismicc@samhsa.hhs.gov](mailto:ismicc@samhsa.hhs.gov).

### **NEW Legal Basics: Medicaid Appeals**

**Tuesday, June 12, 2:00-3:00 ET**

The National Center on Law & Elder Rights (NCLER) is hosting a webinar on Medicaid

## **NEW [An Overview of the NIH All of Us Research Program](#)**

**Thursday, June 21, 1:00-2:00 ET**

*Mid-Atlantic Regional Health Equity Council*

## **NEW [Estate Planning for Special Needs](#)**

**Wednesday, June 27, 12:00-1:15 ET**

*The Parents' Place of Maryland (Maryland Family-to-Family Health Information Center)*

## **THE ADMINISTRATION**

### **Right-to-Try Signed by the President**

As reported in [last week's Update](#), Congress passed the somewhat controversial the "Right to Try Act of 2017" ([S. 204](#)), which allows terminally ill patients to seek unapproved drugs directly from manufacturers without going through the FDA'S "compassionate use" process, which can be lengthy. President Trump signed the bill on Wednesday. See the [White House Fact Sheet](#) on the bill, the [president's remarks](#), and [Vice-President Pence's remarks](#).

### **Anticipated Immigration Rule to Expand the Definition of "Public Charge"**

As explained in the [May 24 Update](#), the administration is expected to issue a proposed immigration rule that would expand the definition of "public charge" for purposes of determining whether an immigrant can come to the US or obtain permanent residency or citizenship. A leaked draft of the proposed rule indicates that it could have the potential to deter families with immigrant members from seeking public benefits, including Medicaid and CHIP for children who are US citizens. A recent [blog post](#) from the Georgetown Center for Children and Families (CCF) summarizes an [issue brief](#) from the Kaiser Family Foundation about the potential impact of the expected rule on the 10.4 million children in the U.S. with at least one non-citizen parent.

## **CONGRESS**

### **President's Proposed Cut in CHIP Contingency Fund**

As explained in the [May 9 Update](#), the president has proposed a "rescissions" package to Congress in order to cut the budget for a number of federal programs using procedures set forth in a rarely used "impoundment" law. Under that law, Congress can move a rescissions bill for a certain period of time (in this case, until June 22) with only a simple majority of 51 votes in the Senate, rather than the 60 votes usually needed to advance legislation under Senate rules. Of the \$15.4 billion in proposed rescissions, the president has proposed cutting \$7 billion from funds in the budget of the Children's Health Insurance Program (CHIP). Of that \$7 billion, about \$5 billion is not available to spend anyway, but the other \$2 billion would be taken from the Child Enrollment Contingency Fund, which provides extra CHIP funding to states that experience an unexpected surge in CHIP enrollment due to a natural disaster, economic downturn or other unusual circumstances. About \$500 billion would remain in the fund. The [Congressional Budget Office has said](#) that it does not anticipate the need for the \$2 billion in contingency funds, so does not think children's insurance coverage would be affected by the cut. However, as reflected in [this blog post](#) from the Georgetown Center for Children and Families (CCF), child health advocates are concerned about reducing a fund intended, by definition, for use in unexpected circumstances. [Ten Senators have introduced a bill](#) with the president's proposed

rescissions, but the future of the legislation is uncertain in both the House and Senate due to controversy about the proposed CHIP cut and other issues. The White House is in negotiations with congressional leaders. See [Trump in Talks to Cancel Some Budget Cutbacks](#) (Politico, 5/23/18).

### **FY 2019 Appropriations**

There are 12 appropriations subcommittees in each chamber of Congress, each of which has jurisdiction over specific federal departments and agencies. Most programs of concern to children with special health care needs and their families are within the jurisdiction of the Subcommittee on Labor, HHS, Education, and Related Agencies (“Labor-HHS”). Each year the House and Senate full appropriations committees decide how much each appropriations subcommittee will receive to spend in the next fiscal year (FY). Last week, the Senate Labor-HHS subcommittee received an increase of \$2.2 billion (1.2 percent) over its FY 2018 allocation for FY 2019, while the House Labor-HHS subcommittee received no increase over the FY 2018 level. Ultimately, though, the two chambers will have to come to an agreement on spending for each program. It is expected that the Labor-HHS subcommittees will begin to take up their bills in late June. Due to its size and controversial issues within its purview, however, the Labor-HHS bill is typically among the last to be enacted, if indeed it is enacted independently rather rolled into a last-minute “omnibus” spending bill, such as the large bill that appropriated funds for most departments in FY 2018.

### **Opioid-Related Legislation**

Multiple congressional committees have developed legislation to address the nation’s opioid epidemic. In April, the Senate Committee on Health, Education, Labor, and Pensions (HELP) approved comprehensive [opioid-related legislation](#), and earlier this month, the House Energy and Commerce Committee [approved over 50 opioid-related bills](#). Now the Senate Finance Committee -- which has jurisdiction over Medicaid, CHIP, Medicare, the Maternal and Child Health Block Grant, and human services programs -- will be taking up opioid legislation as well. On May 23, Senate Finance Committee Chairman Orrin Hatch (R-UT) and Ranking Member Ron Wyden (D-OR) [announced](#) the introduction of [22 bipartisan opioid-related bills](#) sponsored by Finance Committee members. Additional policies may be considered for a markup in the coming weeks. The committee held one hearing on opioid issues in April, and held another on May 29 in Pennsylvania.

### **Health Equity and Accountability Act**

Last week, Representative Barbara Lee (D-CA) introduced the Health Equity and Accountability Act in the House. The bill is intended to help eliminate racial and ethnic health disparities. Over 300 organizations, including Family Voices, endorsed the bill in a [letter](#) sent to Rep. Lee and the other co-chairs of the Minority Tri-Caucus.

## **MEDICAID NEWS, INFORMATION AND RESOURCES**

[Groups File Class Action Lawsuit Against California’s Failure to Adhere to Medicaid Act by Not Providing Appropriate In-Home Care to Children With Disabilities](#) (National Health Law Program, 5/24/18)

### **Resources:**

[What do we know about developmental screenings in Medicaid and CHIP?](#) (blog)

## [Developmental Screenings for Young Children in Medicaid and CHIP](#) (brief)

### **WORTH REPEATING: Electronic Visit Verification (EVV) for Medicaid In-Home Services**

The 21<sup>st</sup> Century Cures Act, enacted last year, requires states to implement “electronic visit verification” (EVV) for Medicaid personal care services (PCS) and home health service (HHCS) provided in a beneficiary’s home in order to ensure that the services are actually delivered. For details, see [this page from Medicaid.gov](#). On May 16, the Center for Medicaid and CHIP Services (CMCS) issued an [Informational Bulletin](#) to states to provide guidance on how to implement an EVV system.

Some provider and patient groups have expressed concern that the agency’s interpretation of PCS and HHCS may be too broad, and that its patient privacy and civil-rights protections may be too weak. See [Worries Abound Over Medicaid Mandate That Caregivers Check In](#) (Disability Scoop, 5/18/18). In order to provide more time to implement the EVV requirement, Senators Lisa Murkowski (R-AK) and Sherrod Brown (D-OH) introduced a bipartisan bill to delay for one year the date by which states must implement an EVV system for PCS. See [Senator Murkowski’s press release](#). Companion legislation was introduced in the House by Representatives James Langevin (D-RI) and Don Young (R-AK).

## **Medicaid Waivers**

### **Here Are Three Big Ways the Trump Administration Could Put Its Mark on Medicaid.**

In this May 16 Washington Post summary of an interview with CMS Administrator Seema Verma, she discusses her view of Medicaid and what waivers the administration might or might not approve. See also [Red States Find There’s No Free Pass on Medicaid Changes from Trump](#) (The Hill, 5/22/18)

### **Work Requirements and Medicaid: What Will Happen to Beneficiaries with Mental Illnesses or Substance Use Disorders?** (The Commonwealth Fund)

## **ACA NEWS, INFORMATION AND RESOURCES**

### **Projections of Insurance Coverage and Premiums**

Last week, the Congressional Budget Office (CBO) and the Joint Committee on Taxation (JCT) released a report -- [Federal Subsidies for Health Insurance Coverage for People under Age 65: 2018-2028](#) – which estimates insurance coverage and premiums for the next decade. They estimate that premiums for benchmark plans will increase by about 15 percent from 2018 to 2019, and by an average of about 7 percent per year between 2019 and 2028. According to the report [summary](#), the 2018-19 increase includes the expected increase in nongroup premiums resulting from healthier people being less likely to obtain insurance after the elimination of the penalty related to the individual mandate.” The CBO and JCT also estimate that in 2018 about “two-thirds of the insured population under 65 will have coverage through an employer, and roughly a quarter will be enrolled in Medicaid or the Children’s Health Insurance Program (CHIP). A smaller number will have nongroup coverage, coverage provided by Medicare, or coverage obtained from various other sources. For example, about 4 percent, or 9 million people, are projected to obtain coverage through the marketplaces.” See also [CBO: Obamacare Premiums to Rise 15 Percent in 2019](#) (The Hill, 5/23/18).

## TRICARE

### [Seeking Referrals or Prior Authorizations for Specialty Care with TRICARE](#)

Under some TRICARE programs, patients may need a referral or prior authorization from their Primary Care Manager (PCM) to seek care from a specialty provider. (From TRICARE Benefit Update, 5/24/18.)

### [Explaining TRICARE Annual Cost Increases](#) (TRICARE Benefit Update, 5/22/18)

## OTHER NEWS & INFORMATION

### **Transportation of Service Animals on Airlines**

On May 23, the Department of Transportation (DOT) published an [Advanced Notice of Proposed Rulemaking \(ANPRM\)](#) regarding regulations of service animals under the Air Carrier Access Act (ACAA). Because rulemaking is a lengthy process, the Department simultaneously issued an [Interim Statement of Enforcement Office Priorities](#) to inform the public about how it plans to target enforcement of the Act with respect to the transportation of service animals in airplane cabins until the regulations are revised. According to the Statement, the DOT's "Enforcement Office will focus on ensuring the transport of the most commonly used service animals, such as dogs, cats and miniature horses [?!], but may take action against carriers regarding the transport of other service animals on a case-by-case basis." According to the Statement: "Airlines are expected to continue to comply with the existing service animal requirement which allows U.S. airlines to deny transport only to certain unusual service animals such as snakes, other reptiles, ferrets, rodents, and spiders." The Department is accepting public comments on the ANPRM, and has specifically asked for feedback on [ten questions](#) related to topics such as documentation required by passengers, leash/harness requirements, and how to safely transport large service animals. Comments are due on June 7, and can be submitted at <https://www.regulations.gov/document?D=DOT-OST-2018-0067-0019>.

## OTHER RESOURCES

[Lessons in Health Coverage Consumer Assistance: Best Practices and Future Challenges](#) (Community Catalyst report, May 2018, 10 pp.)

[New Law Helps States Pay for Mental Health and Substance Abuse Services with Federal Foster Care Funds](#) (National Academy for State Health Policy, 5/29/18)

A [blog post](#) from the Georgetown Center on Children and Families (CCF) discusses a new "[City Health Dashboard](#)" that provides data on 36 key measures of health and health-related factors for 500 U.S. Cities.

## YOUR INPUT SOUGHT

[Listed in order of due date.]

### **Transportation of Service Animals on Airlines**

#### **Comments due June 7**

Please see above, under "Other News & Information."

Comments can be submitted at <https://www.regulations.gov/document?D=DOT-OST-2018-0067-0019>.



## Transparency of Hospital Charges to Prevent “Surprise Medical Bills”

### Comments due June 25

In a [proposed rule](#) on Medicare hospital payments, CMS included a request for public comments “regarding barriers preventing providers from informing patients of their out of pocket costs; what changes are needed to support greater transparency around patient obligations for their out of pocket costs; what can be done to better inform patients of these obligations; and what role providers should play in this initiative.” See this CMS [fact sheet](#). The precise questions on which comments are sought can be found [here](#). For more details, see the [April 26 Washington Update](#). Comments can be submitted [here](#).

### OF POSSIBLE INTEREST

[Cameras on Premises Let Family In, Keep Germs Out](#) (Fierce Healthcare, 5/29/18)

[Walmart \[Labs\] Announces Return-To-Work Program for Family Caregivers](#) (Forbes, 5/24/18)

[The 1,500 “Missing” Migrant Children: An Immigration Expert Explains What You Need to Know](#)  
*Did the Trump administration lose track of hundreds of kids? Not exactly.* (Vox.com, 5/29/18)

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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](mailto: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.*