



# FAMILY VOICES<sup>®</sup>

Washington DC Update  
February 8, 2019

## **GREETINGS FROM WASHINGTON!**

Not surprisingly, the main topic of conversation in DC this week is the State of the Union Address delivered by President Trump on Tuesday, February 5. The president mentioned several health-related topics, including prescription drug prices, HIV/AIDS, childhood cancer, and paid family leave. In other news, a bipartisan House-Senate conference committee is carrying on negotiations regarding border security and whether/how much to provide for a “wall” on the southern US border. Absent another temporary funding bill, the federal government will again be subject to a partial shut-down if an agreement is not reached and signed into law by the president no later than February 15. Read about these issues and more in this week’s Update.

February is **Black History Month**. Visit the [Black History Month](#) webpage of the HHS Office of Minority Health for materials, upcoming events, and health resources.

## **SPREAD THE WORD: Federal Trade Commission Scam Warning**

The Federal Trade Commission is getting reports about people pretending to be from the Social Security Administration (SSA) and trying to get your Social Security number and your money.

- The SSA will *never* call and ask for your Social Security number. It will not ask you to pay anything. It won’t call to threaten your benefits.
- ***Your caller ID might show the SSA’s real phone number (1-800-772-1213), but that’s not the real SSA calling.*** Never give or confirm your Social Security number or its last 4 digits to anyone who contacts you in this way. Do not give a bank account or credit card number – ever – to anybody who contacts you by phone asking for it.
- Remember that anyone who tells you to wire money, pay with a gift card, or send cash is always a scammer no matter who they say they are.

***BE CAREFUL OUT THERE!*** With the drastic weather conditions of late, you might want to check out these tips on [Preventing Winter Injuries \(from TRICARE\)](#), including information about heart attacks, hypothermia, frostbite, and falls.

**ACA Enrollment:** Due to Hurricane Michael, a Special Enrollment Period (SEP) has been established for certain individuals in **Florida** and **Georgia** so that they have more time to enroll in a health insurance plan. In **Florida**, eligible consumers will have until **February 16, 2019**, to enroll in Exchange coverage. In **Georgia**, qualifying consumers will have until **February 20, 2019**, to enroll. See details in the [CMS announcement](#) and the [January 17 Washington Update](#).

**SAVE THE DATE! 2019 Family Leadership Conference, May 8-10, Washington, DC, “Families as Partners Shaping Systems Change.”**

JOIN US! The 2019 Family Voices Leadership Conference will bring together a diverse community of family and youth leaders, family members, professional partners, and other stakeholders from across the country. Together we will learn from each other, share resources and expertise, explore ways to improve supports to families, learn new strategies for managing nonprofits, and increase capacity for families to partner in systems change. Watch the [Family Voices Conference Web Page](#) for more information!

**UPCOMING WEBINARS AND CALLS**

**SERIES: [Learning and Reflection Forum Series](#)**

*Leadership Institute for Cultural Diversity and Cultural and Linguistic Competence*

To discuss challenges and opportunities associated with leading cultural diversity and cultural and linguistic competence within developmental disability agencies.

**[How We are Leading: Voices from Alumni](#)**

**Thursday, March 14, 2:00-3:30 pm ET**

**NEW Save the dates:**

**April 11, 2019 - 2:00-3:30 pm ET**

Leading through Conflict: Overcoming Resistance

**May 16, 2019 - 2:00-3:30 pm ET**

To Be Determined (TBD)

**June 13, 2019 - 2:00 pm-3:30 pm ET**

Benchmarks, Measures & Frameworks at the Intersection of Cultural and Linguistic Competence and Disability

**[All of Us Research Program: A look Into Local Enrollment!](#) (On the ground at the San Ysidro Health Center)**

**Tuesday, February 12, 4:00-5:00 pm ET** (*Register by February 11, 2019*)

*National Hispanic Medical Association*

**[Promising Practices in Managed Long-Term Services and Supports: Network Adequacy and Accessibility](#)**

**Friday, February 15, 2:00-3:30 pm ET**

*Community Living Policy Center*

**NEW [Guidelines-Based Asthma Care Coverage in Medicaid: New Tools for Stakeholders](#)**

**Tuesday, February 19, 1:00-2:00 pm ET**

*Sponsored by the American Lung Association*

**[NEW Operationalizing State-Community Partnerships for SOC \[System of Care\] Expansion](#)**

**Wednesday, February 20, 2:30-4:00 pm ET**

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

**[NEW The AAKOMA Project: Engaging African-American Youth and Youth of Color in Addressing Depression and Other Mental Health Needs](#)**

**Thursday, February 21, 1:30-3:00 pm ET**

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

**[NEW Building Partnerships and Educating Families and Professionals about Supported Decision Making](#)**

**Thursday, February 21, 3:00-4:15 pm ET**

*Family Voices and Quality Trust*

**[Starting and Sustaining a Youth Advisory Board, Part 1: Youth Voice](#)**

**Wednesday, February 27, 12:00-1:00 pm ET**

*Family Voices*

This webinar series is especially for organizations that seek to develop a youth advisory board.

**THE COURTS**

**[Maryland Judge Dismisses Lawsuit Seeking to Protect Affordable Care Act](#)**

(Washington Post, 2/1/19)

**THE ADMINISTRATION – STATE OF THE UNION ADDRESS**

In Tuesday night's [State of the Union Address](#) (video and transcript), President Trump brought up several health-related topics, including the need to address high prescription drug prices. He revealed that his federal budget for FY 2020 will propose spending \$500 million over the next 10 years to fund research on childhood cancer, and will propose that Congress "make the needed commitment to eliminate the HIV epidemic in the United States within 10 years." Read the [president's HIV plan](#). See [Trump Highlights Health Agenda with Vow to Lower 'Unfair' Drug Prices](#) (Kaiser Health News, 2/6/19). (This article reviews the health-related portions of the president's State of the Union Address, and reactions from both sides of the aisle.) In addition, the president mentioned paid family leave, saying "I am also proud to be the first President to include in my budget a plan for nationwide paid family leave, so that every new parent has the chance to bond with their newborn child." He did not go into detail, but [reportedly](#), the president's daughter, Ivanka, has been working with Sen. Marco Rubio on legislation that would allow people to take leave with pay drawn from their future Social Security benefits.

## CONGRESS

### Negotiations on Funding for “The Wall”

Seventeen members of a bipartisan House-Senate conference committee are currently negotiating the appropriations bill for the Department of Homeland Security. The focus of the negotiations is on border security, specifically whether or not to build a wall on the southern border of the US, and if so, how much money to spend on it. Both Senate Majority Leader Mitch McConnell (R-KY) and House Speaker Nancy Pelosi (D-CA) have encouraged the committee to negotiate without constraints. See [Unshackled by Leadership, Appropriators Ready to Deal on Border](#) (Roll Call, 2/6/19). As of this writing, there seems to be cautious optimism that conferees can reach an agreement *among themselves* in time for Congress to act by February 15, the expiration date for the short-term spending bill (“continuing resolution”) that is currently funding the government departments for which FY 2019 appropriations bills have not yet been enacted. Even if the conferees produce an agreement, however, it is not certain that the bill would pass both the House and Senate and be signed by the president. See [Congressional Negotiators Seek Contours of Border Deal as Shutdown Looms](#) (Washington Post, 2/6/19). If there is still a stalemate on the 15<sup>th</sup>, then there will either be another partial government shut-down or another short-term spending bill. Alternatively, the president could declare a “national emergency” to fund the wall without a congressional appropriation for that purpose. Such a declaration would likely be challenged in the courts.

### Hearings on Various Healthcare Issues and Immigrant-Family Separation

Multiple committees in the House and Senate have been holding hearings or seeking information on a variety of healthcare and related issues. On the Senate side, there has been bipartisan action. Senate Finance Committee Chairman Chuck Grassley (R-IA) and Ranking Democrat Ron Wyden (D-OR) invited seven major [drug manufacturers to testify about their prices](#). And, in preparation for drafting legislation on surprise medical bills, a bipartisan group of senators sent letters to insurers and medical providers posing detailed questions about their billing and payment procedures. See [Bipartisan Senators Ask Industry for Information on Surprise Medical Bills](#) (The Hill, 2/5/19); [Ideas to Curb Surprise Medical Bills Percolate with Rare Bipartisan Push](#) (Kaiser Health News, 2/5/19). On the House side, the new Democratic majority is holding hearings on the Affordable Care Act and people with pre-existing conditions in the [Committee on Energy and Commerce, Subcommittee on Health](#) and the [Committee on Education and Labor](#). The House Judiciary Committee will be holding an [oversight hearing](#) on family separation policy on February 12, with witnesses from the Immigration and Customs Enforcement, Customs and Border Protection, Department of Justice, and Department of Health and Human Services.

## MEDICAID AND CHIP NEWS, INFORMATION AND RESOURCES

### MEDICAID WAIVERS

Approved and pending Medicaid waiver applications can be found on [Medicaid.gov](#).

**REMINDER:** The Kaiser Family Foundation regularly updates its state-by-state §1115 [Medicaid Waiver Tracker](#), and also provides related waiver [resources](#) and [definitions](#).

## OTHER MEDICAID RESOURCES

The Center on Budget and Policy Priorities (CBPP) has updated its [Medicaid Works: State Fact Sheets](#).

## OTHER NEWS, INFORMATION, AND RESOURCES

### Patient Engagement at the FDA

**From the Patient Affairs Staff (PAS), Food and Drug Administration, U.S. Department of Health and Human Services (1/30/19):**

FDA's Patient Affairs Staff will continue working with patients, caregivers, and advocates in 2019. FDA believes patients are experts when it comes to their health conditions. Understanding the patient experience and incorporating patient feedback into the work is an agency-wide priority. Last year, Patient Affairs launched several initiatives to help better support and connect with patients, including:

- released the first video from the [Patients Matter video series](#)
- kicked off the [FDA/NORD Rare Disease Listening Session pilot](#) by hearing from patients and caregivers who shared their experiences [living with hemophilia](#)
- hosted the [inaugural meeting](#) of [Patient Engagement Collaborative \(PEC\)](#) in collaboration with the Clinical Trials Transformation Initiative (CTTI)

Want to learn more about Patient Affairs and ways you can get involved? Check out the recent [FDA Voices post](#), or connect with us on Twitter [@FDAPatientInfo](#).

### **WORTH REPEATING: New Federal Policy on Restraint and Seclusion in Schools**

On January 17, Secretary of Education Betsy DeVos announced a new department initiative to address the problem of restraint and seclusion of school children with disabilities. See [U.S. Department of Education Announces Initiative to Address the Inappropriate Use of Restraint and Seclusion to Protect Children with Disabilities, Ensure Compliance with Federal Laws](#) (Department of Education press release, 1/17/19). The Department's Office for Civil Rights (OCR), in partnership with the Office of Special Education and Rehabilitative Services (OSERS), will oversee the initiative, which will include compliance reviews; civil rights data collection; and technical assistance for schools and education agencies on the legal requirements of Section 504 of the Rehabilitation Act relating to the use of restraint and seclusion on children with disabilities. See [DeVos to Examine the Use of Restraint and Seclusion on Students with Disabilities: Civil rights activists and the Trump administration's Education Department find themselves in the rare position of being on the same side of an issue](#). (US News, 1/17/19); [Initiative Tightens Scrutiny on Restraint, Seclusion in Spec. Ed.](#) (Education Week, 1/23/19).

### From the CDC:

### Updated CDC Milestone Tracker for Ages 0-5 Available in English, Spanish

The Centers for Disease Control and Prevention's [Milestone Tracker – a free app](#) for easily tracking a child's early development – has been updated, and now is available in English and Spanish. The app adds to the suite of free, family-friendly materials from *Learn the Signs. Act Early*. **Download the app in [English](#) or [Spanish](#).**

## **WORTH REPEATING: Tools for Cross-Cultural Communication and Language Access Can Help Organizations Address Health Literacy and Improve Communication Effectiveness**

This webpage includes links to many materials, such as the “[Primer: Cultural Competency and Health Literacy](#)” from the University of Maryland School of Public Health, which provides teaching tools to deliver culturally appropriate healthcare services to diverse populations.

### **From Partner Organizations:**

**Got Transition has translated its quiz, “[Are You Ready to Transition to Adult Care?](#)” into [Spanish](#).** The online quiz asks key questions to help prepare young people for transition, and the site includes tips and linked resources.

### **Engaging Families in Advisory Roles – 5 Top Tips**

From the Lucile Packard Foundation for Children’s Health

### **A New Approach to Accessing Family Engagement in Health Care Systems**

A recent issue brief from Family Voices, [A Framework for Assessing Family Engagement in Systems Change](#) was discussed during a January 23 webinar sponsored by the Lucile Packard Foundation for Children’s Health. The [webinar slides and materials](#) are now available.

### **Developmental Screening Measures Map**

The National Academy for State Health Policy (NASHP) features its updated [developmental screening measures map](#), which tracks voluntary state reporting of the developmental screening measure for children enrolled in Medicaid and CHIP. Check out other resources at the [Healthy Child Development State Resource Center](#), supported by the David and Lucile Packard Foundation. If you have a resource to request be featured, please email [ehiggins@nashp.org](mailto:ehiggins@nashp.org).

### **New Report on Paid Family Leave and the Disability Angle**

The Arc and the National Center for Children in Poverty (NCCP) at Columbia University’s Mailman School of Public Health have published a new report, [Disability Perspectives on Paid Leave: A Qualitative Analysis of Leave-taking among Workers Affected by Disabilities or Serious Health Conditions](#). As explained in The Arc’s [press release](#), “this report examines how workers with disabilities and working caregivers of people with disabilities use, need, and benefit from paid family and medical leave....Findings offer key insights on how existing leave policies can become more disability-inclusive and highlight the need for a comprehensive, national paid leave policy.”

### **Resources on Electronic Visit Verification (EVV)**

[Applied Self-Direction](#) has developed a number of resources to help self-direction programs implement electronic visit verification (EVV). These resources include:

- A [directory of vendors](#) with 25 EVV vendors interested in serving self-direction programs
- A [compilation of EVV websites](#) by state
- A [blueprint](#) to help stakeholders develop their own EVV products, as well as to help stakeholders evaluate existing EVV products to determine whether these options will be compatible with the unique operational needs of self-direction

- A [tip sheet](#) on implementation approaches to help states and others ensure EVV systems mitigate fraud while supporting the flexibility of self-direction

You can view all of these resources, along with EVV webinar slides and recordings, on Applied Self-Direction's website under the [EVV Resources](#) section.

### **WORTH REPEATING: Psychosocial Factors in Children and Youth with Special Health Care Needs and Their Families**

(American Academy of Pediatrics Clinical Report, published in *Pediatrics*, January 2019)

The purpose of this clinical report is to raise awareness of the impact of psychosocial factors on the health and wellness of CYSHCN and their families, and to provide guidance for pediatric providers to facilitate and coordinate care for the benefit of these children and families.

### **WORTH REPEATING: New Resources Added to the National Standards for CYSHCN Toolkit**

The National Academy for State Health Policy and the Association of Maternal & Child Health Programs have added new resources to the [National Standards for Children and Youth with Special Health Care Needs Toolkit](#).

### **WORTH REPEATING: State Maternal and Child Health Legislation Database**

The National Conference of State Legislatures' [Maternal and Child Health Database](#) tracks enacted state laws on 14 different topics that affect the health and well-being of U.S. mothers and children. You can search legislation by state, topic, keyword or year.

## **YOUR INPUT SOUGHT**

### **HHS Seeks Public Feedback on [Modifying HIPAA Privacy Rules](#) – Due February 12, 2019**

The Office of Civil Rights (OCR) of the Department of Health and Human Services (HHS) has published a Request for Information (RFI) asking the public for comments on how regulations implementing the Health Insurance Portability and Accountability Act (HIPAA) can be improved to “facilitate efficient care coordination and/or case management, and/or promote the transformation to value-based health care,” including rule changes that would encourage providers and other covered entities to share treatment information with parents, loved ones, and caregivers of adults facing health emergencies (with a particular focus on the opioid crisis). Comments are due no later than **February 12, 2019**. [Read the RFI and submit comments](#).

### **[Consideration of pain in adult and child disability claims](#) – Due February 15, 2019**

The Office of Disability Policy, Social Security Administration (SSA) has issued an Advance Notice of Proposed Rulemaking (ANPRM) to solicit public comments and supporting data related to the consideration and documentation of pain in the medical evidence used in connection with claims for benefits. SSA will use the responses to the questions listed in the ANPRM and any other relevant research and data obtained to determine whether and how to propose revisions to the current policy regarding the evaluation of pain. Comment [here](#).

### **[Notice of Benefit and Payment Parameters](#) – Due February 19, 2019**

On January 17, the Department of Health & Human Services (HHS) [announced](#) the release of the [2020 “Notice of Benefit and Payment Parameters”](#) (NBPP) [[PDF](#), 95 pp]. Once finalized this rule will govern

key aspects of the Affordable Care Act (ACA), including the operation of the federal and state marketplaces, benefit standards for health plans, and premium stabilization programs. See also the [CMS Fact Sheet](#) and the [2020 Draft Letter to Issuers](#). For more details, see the [January 30 Washington Update](#) (under “ACA”); a [blog post](#) from the Georgetown Center for Health Insurance Reforms (CHIR); and “[The 2020 Proposed Payment Notice, Part 1: Insurer and Exchange Provisions](#)” (Health Affairs blog, 1/18/19). Comments on the rule are due **February 19, 2019**, and can be submitted via [Regulations.gov](#).

### **[Pain Management Task Force Draft Report – Due April 1, 2019](#)**

The Comprehensive Addiction and Recovery Act of 2016 (CARA), requires that the public be given at least ninety (90) days to submit comments on any proposed updates and recommendations developed by the Pain Management Best Practices Inter-Agency Task Force (Task Force). The Task Force is requesting comments on the Draft Report on Pain Management Best Practices: Updates, Gaps, Inconsistencies, and Recommendations (hereinafter referred to as Draft Report). [Submit comments](#).

### **OF POSSIBLE INTEREST**

[These Moms Are Building a Forever Home for Their Adult Autistic Children](#) (Washington Post, 1/29/19)

[With Mom’s Green Card on the Line, Family Forgoes Autism Services for Citizen Child](#) (Kaiser Health News, 2/1/19)

[With Time Ticking Away, Clinicians Scramble to Save Newborn Twins from the Disease that Took Their Brother](#) (STAT News 2/5/19)

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](mailto:jguerney@familyvoices.org).

Yours truly,  
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