



# FAMILY VOICES<sup>®</sup>

Washington DC Update  
January 30, 2019

## GREETINGS FROM WASHINGTON!

The big news in DC this week is the end of the partial government shut-down, at least until February 15. In the health-policy world, the big news is the release of the proposed “Notice of Benefit and Payment Parameters” (NBPP) for 2020, the annually-issued rules governing ACA marketplaces, insurance benefits, risk adjustment, and more. Public comments on the NBPP are due on February 19. Another significant development affecting children with special health care needs is the release of a new initiative from the Department of Education to address the inappropriate use of restraint and seclusion for school children with disabilities. Read about these developments and find numerous new resources in this week’s Update.

**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

### [Building Capacity to Include People Who Have Disabilities](#)

Wednesday, January 30, 12:00-1:00 pm ET

*Association of University Centers on Disabilities*

### [Successfully Engaging Members in Plan Governance](#)

Wednesday, January 30, 12:30-2:00 pm ET

*Centers for Medicare and Medicaid Services in collaboration with The Lewin Group and the Center for Consumer Engagement in Health Innovation*

- **NOTE:** This webinar is intended for staff of Medicare-Medicaid Plans, Dual Eligible Special Needs Plans (D-SNPs), and PACE organizations who are interested in engaging members in plan governance through consumer advisory committees or other strategies.

## **NEW [Circle of Care, a Tool for Mental Health Caregivers, Providers and Policymakers](#)**

**Wednesday, January 30, 1:00 pm ET**

*National Alliance for Caregiving and National Alliance on Mental Illness (NAMI)*

Based on the 2018 guidebook, [A Circle of Care: A Guidebook for Mental Health Caregivers](#), which emerged from the 2016 study [On Pins and Needles: Caregivers of Adults with Mental Illness](#).

## **NEW [I/DD and Mental Health: What We Are Learning About Challenges and Needs](#)**

**Wednesday, January 30, 2:00-3:00 pm ET**

*The Arc*

## **[ABLE Accounts and Special Needs Trusts](#)**

**Thursday, January 31, 2:00-3:30 pm ET**

*National Disability Institute*

To prepare for the webinar, you are encouraged to review:

- [The ABLE Materials Toolkit](#) - A centralized location of printable ABLE-related information which will increase your awareness and understanding of ABLE accounts.
- [“ABLE Accounts and SNTs” How to Choose?”](#) - Explains the similarities and differences between ABLE accounts and SNTs.

Real time captioning will be provided for this webinar. For other accommodation requests, questions about the webinar, or the registration process, please contact [info@ablenrc.org](mailto:info@ablenrc.org).

## **NEW [Cultivating and Securing Safe Spaces \[for immigrants\] in Health Care Centers](#)**

**Thursday, January 31, 5:30-7:00 pm ET**

*National Immigration Law Center*

## **NEW [All of Us Includes Disability](#)**

**Wednesday, February 6, 12:30-1:30 pm ET**

*Association of University Centers on Disability (AUCD) and the American Association on Health Disability (AAHD)*

(About outreach efforts to ensure that people with disabilities participate in the [NIH All of Us Research Program](#).)

## **[SERIES: Genetic Counselors in the Genomic Era – Public Health Genetics and Precision Medicine Roles](#)**

*Sponsored by the National Society of Genetic Counselors (NSGC)*

### **Save the Dates:**

- **Direct-To-Consumer Genetic Testing**  
**Wednesday, February 6, 1:00-2:00 pm ET**
- **Disparities in Genetic Services and Privacy**  
**Tuesday, April 9, 12:00-1:00 pm ET**
- **Precision Medicine and Return of Results**  
**Tuesday, May 14, 12:00-1:00 pm ET**
- [An Overview of Regional Genetics Networks \(ARCHIVED\)](#)

## **[NEW Digging Deeper on the Public Charge Policy Changes in the State Department's Foreign Affairs Manual](#)**

**Thursday, February 7, 1:00-2:30 pm ET**

*The Protecting Immigrant Families Campaign*

## **NEW SERIES: Learning and Reflection Forum**

*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.

### **[Leadership Styles](#)**

**Thursday, February 7, 2:00-3:30 pm ET**

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

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

## **[NEW 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*

## **[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 “SHUT-DOWN”**

No doubt you have heard that the partial government “shut-down” has been ended until at least February 15 in order to allow time for Congress and President Trump to negotiate over funding for a “wall” on the nation’s southwest border. Fortunately, this means that important services and benefits will resume, including those provided through the Indian Health Service, Food and Drug Administration, and Department of Agriculture Nutrition Assistance programs.

## **THE ADMINISTRATION**

### **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).

[Trump Boosts Fight against Surprise Medical Bills](#) (The Hill, 01/27/19).

## [WORTH REPEATING: Maternal and Child Health Bureau Announces Phase 1 Winners of the Challenge](#)

The Maternal and Child Health Bureau has selected 7 winners from Phase 1 of the Care Coordination for Children with Special Health Care Needs Challenge. Each Phase 1 winner was awarded a share of \$100,000 and will move on to Phase 2 to develop their prototype and begin small-scale testing through July 2019. [See the winners.](#)

## **CONGRESS**

### **Money-Follows-The-Person (MFP) Program Extended Temporarily**

On January 25, the president signed the Medicaid Extenders Act of 2019 ([H.R. 259](#)), which was approved in the Senate by unanimous consent on January 17. The Act provides \$112 million for [Money Follows the Person](#), the estimated cost of a three-month extension, which is available for states to spend until September 30, 2019. It also extends the Medicaid [home-and-community-based-care spousal impoverishment protections](#) until March 31, 2019.

### **Upcoming Hearings**

Earlier this month, House Energy and Commerce Committee Chairman Frank Pallone (D-NJ) [announced](#) that the committee would be holding a hearing on the federal district court ruling that the Affordable Care Act is unconstitutional, and a hearing about the administration's separation of immigrant families and the safety of immigrant children under the care of the Department of Health and Human Services. Dates have not yet been announced. On January 10, the Association of Maternal and Child Health Programs, Association of University Centers on Disabilities, and Family Voices sent a joint letter to committee leaders urging them to address the considerations of children and youth with special health care needs, including those with disabilities, in these hearings. On January 29, the House Ways and Means Committee held a [hearing on protecting Americans with pre-existing conditions](#), and the Senate Finance Committee held a [hearing on Drug Pricing in America: A Prescription for Change, Part: A Prescription for Change, Part I.](#)

## **THE COURTS**

Kentucky residents have filed a lawsuit challenging the administration's re-approval of a Medicaid waiver that would establish "community engagement" requirements for certain Medicaid beneficiaries. Eligibility for these individuals would be contingent on their working or engaging in other specified activities for a certain number of hours per month. Last year a [court overturned](#) the administration's initial approval of the waiver, finding that the Centers for Medicare and Medicaid Services (CMS) did not adequately consider how the waiver would further the aim of the Medicaid program – to provide medical assistance to low-income individuals. After a court-mandated public comment period, CMS re-approved the waiver. The plaintiffs claim that CMS again failed to consider

the purpose of the Medicaid program in the waiver-approval process. See [Medicaid Recipients File Suit Again to Block Bevin's Work Requirements and Premiums](#) (Lexington Herald Leader, 1/15/19).

## MEDICAID AND CHIP NEWS, INFORMATION AND RESOURCES

### MEDICAID WAIVERS

#### [CMS Approves Arizona's Medicaid Community Engagement Demonstration Amendment](#)

(CMS press release, 1/18/19). See [CMS approves 8th state for Medicaid work requirement](#) (Healthcare Dive, 1/22/19).

**WORTH REPEATING:** [Tennessee](#) proposes to amend its demonstration to add community-engagement requirements as a condition of eligibility for certain individuals age 19 through 64 who are enrolled in the parent/caretaker-relative eligibility group, a very low-income population. The federal public comment period for that proposal is open until **February 7**. For updates on other §1115 waiver proposals see the Kaiser Family Foundation's [Medicaid Waiver Tracker: Approved and Pending Section 1115 Waivers by State](#).

**Second Legal Challenge to Kentucky Medicaid Waiver.** (See "The Courts" section, above.)

### MEDICAID RESOURCES

#### [Medicaid in the Territories: Program Features, Challenges, and Changes](#)

(Kaiser Family Foundation Issue Brief, 1/25/19)

#### [How are States Using Medicaid to Pay for Home Visiting? New Paper Offers More Clarity](#)

(*Say Ahhh!*, Blog of the Georgetown Center on Children and Families, 1/22/19)

### AFFORDABLE CARE ACT

#### OPEN ENROLLMENT

The only jurisdictions that are still open for insurance-coverage enrollment are New York and the District of Columbia. In both, the enrollment period ends on **January 31**.

#### NOTICE OF BENEFIT AND PAYMENT PARAMETERS (NBPP)

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](#). Comments on the rule are due **February 19, 2019**, and can be submitted via [Regulations.gov](#).

From the consumer perspective, there are both positive and negative elements of the NBPP, of which a few are noted below. The following explanations are drawn from a more thorough [blog post](#) from the

Georgetown Center for Health Insurance Reforms (CHIR). In-depth information can also be found in "[The 2020 Proposed Payment Notice, Part 1: Insurer and Exchange Provisions](#)" (Health Affairs blog, 1/18/19).

**"Premium Adjustment Factor."** The administration proposes to change the way it calculates the ACA's "Premium Adjustment Factor." Ultimately, this would decrease premium tax credits and increase out-of-pocket costs for consumers, including those with insurance provided by their employers. (See the explanation in the [CHIR blog post](#).)

**Promotion of generic drugs.** Some significant proposed changes involve prescription-drug benefits:

- Insurance plans would be permitted to **change their drug formularies mid-year**. They could take a brand name drug off their [formularies](#) or to move it to a higher cost-sharing tier. Insurers would have to give enrollees at least 60 days' notice of the formulary change. *HHS asks for comments* on whether a 90- or 120-day notice period would be more appropriate. This proposal would *not* preempt state law.
- Insurance plans could **exclude a brand-name drug from its "essential health benefits"** (EHBs) if they cover a generic equivalent. As a result, the brand-name drug would not be subject to annual or lifetime dollar limits, and patients' cost-sharing towards the drug would not count towards their annual cap on out-of-pocket spending. Patients could seek exceptions if only the brand name drug is medically appropriate. *HHS asks for comments* on whether this policy should preempt any conflicting state laws, and whether an insurer's decision to exclude a drug from EHB should be considered an adverse benefit determination that would trigger an enrollee's right to appeal.
- HHS proposes that if a consumer uses a **manufacturer's coupon** to cover the copayment or coinsurance towards a brand-name drug when a generic equivalent is available, the insurer would not be required to count that cost-sharing towards the consumer's annual cap on out-of-pocket spending. *HHS seeks comments* on whether this policy should preempt state law.

**Navigators.** HHS proposes to eliminate the requirement that Navigators provide consumers with post-enrollment assistance; "streamline" Navigator training materials; and encourage Navigators and other assisters to enroll clients through web-brokers that meet certain standards.

**New Special Enrollment Period Opportunity.** HHS proposes to expand the group of individuals that would have a special enrollment period (SEP) to include individuals enrolled in off-marketplace individual market coverage who become eligible for the ACA's premium tax credits due to reduced income. Previously only those already enrolled in a marketplace plan or in employer-sponsored coverage would qualify for such a SEP.

**Silver Loading.** Notably, and on the positive side for consumers, the proposed NBPP does *not* ban "silver loading." (The administration had signaled that it might do so.) Silver loading refers to the practice of concentrating premium increases in an insurer's "silver plan." Premium tax credits are based on the cost of silver-level plans, so are greater when silver-plan premiums are higher, whether or not the consumer purchases a silver-level plan. Silver loading arose when the government stopped reimbursing insurers for offering plans with cost-sharing reductions (CSRs), as they are required to do by law. If CSR payments to insurers are not re-instituted, and silver loading were not permitted, then premiums would go up across all plans offered by an insurer, meaning that most consumers would have to pay higher premiums.

**Automatic Re-enrollment.** The proposed NBPP does *not eliminate* automatic re-enrollment in federally-facilitated marketplace plans for eligible enrollees who have not taken action to re-enroll or select a new plan. Without automatic re-enrollment, many people would likely lose coverage.

## TRICARE

### [Learn More about Your Benefit with 2019 TRICARE Resources](#)

Jan. 22, 2019

### [Save Money at the Pharmacy: Understanding TRICARE Prescription Drug Types](#)

Jan. 16, 2019

#### **WORTH REPEATING: Government Shutdown: Some Allotment Payments Affected**

The partial government shutdown affects allotments used by some TRICARE patients to pay enrollment fees and dental premiums. TRICARE is not able to process payments made through the U.S. Coast Guard pay center. However, patients will *not* be disenrolled for nonpayment, and TRICARE will continue to process claims during the shutdown. Beneficiaries do not need to take action at this time. For details, see [Government Shutdown: Some Allotment Payments Affected](#) (TRICARE Benefits Update, 1/14/19).

Sign up for TRICARE email updates at [www.tricare.mil/subscriptions](http://www.tricare.mil/subscriptions). Connect with TRICARE on Facebook and Twitter at [www.facebook.com/tricare](http://www.facebook.com/tricare) and [www.twitter.com/tricare](http://www.twitter.com/tricare).

## OTHER NEWS, INFORMATION, AND RESOURCES

### **From the Administration on Community Living (ACL):**

Learn more about [ACL's Business Acumen Initiative](#). Medicaid, Medicare, Accountable Care Organizations, private insurers, and other private pay models offer opportunities for community-based organizations to tap into new revenue streams outside of government grants. However, securing contracts with such payers – and performing effectively under them – requires thinking and operating differently. The Business Acumen Initiative can help states and community-based organizations build networks and respond to delivery system changes, including technical assistance, building business capacity for successful contracting with integrated care entities, and developing pathways to sustainability.

### **From the CDC:**

[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:**

#### **[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.

## **[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](#).

## **[State Strategies for Promoting Children’s Preventive Services](#)** – updated

The National Academy for State Health Policy has [updated maps](#) and an accompanying [chart](#) featuring state-specific Medicaid or Children’s Health Insurance Program improvement projects, measures, and incentives that promote children’s preventive services.

## **[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.

## **[State Efforts to Protect Consumers from Balance Billing](#)**

(Blog of the Georgetown Center on Health Insurance Reforms, 1/22/19)

## **YOUR INPUT SOUGHT**

**[NEW Notice of Benefit and Payment Parameters](#)** – **Due February 19, 2019.** (See “ACA News,” above.)

**[NEW 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.](#)

**[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](#).



**Medicaid §1115 Waivers** – State waiver proposals are subject to both state and federal comment periods. See the “Medicaid waivers” section above for open federal comment periods.

## **OF POSSIBLE INTEREST**

### **Balancing The Risks and Benefits of Opioids for Children**

*The Checkup* (New York Times blog, 1/28/19)

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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