



# FAMILY VOICES<sup>®</sup>

Washington DC Update  
October 3, 2019

## Greetings from Washington!

Not a lot happened during the past week in Washington...with respect to health care, that is. The president signed the Autism CARES Act but, otherwise, policymakers and politicians have been preoccupied with other matters (i.e., the impeachment inquiry), which may interfere with the ability of the two parties and two branches of government to get much accomplished in the way of legislation. In the judicial branch, however, a notable decision has been rendered: a federal appeals court ruled that the Department of Justice can move forward with a suit against Florida regarding the placement of children in nursing homes. With respect to regulations and resources, this Update includes (among other things) information about: [The Roadmap to Behavioral Health](#) (for families); a [statement from the FDA about patient engagement in medical device clinical investigations](#); [quality ratings for health plans](#) sold in the Marketplace; and a [Final Rule](#) on “Patients Over Paperwork” (in the Medicaid section below). And, please note...

**IT’S RECESS!** Members of Congress are home on a two-week recess (through October 14), providing an opportunity for you to see them in their local offices or at town halls or other public events. It’s a great chance to educate them about CYSHCN and their families, and about your Family-to-Family Health Information Center or other programs. To get contact information for your Members of Congress, see [www.contactingcongress.org](http://www.contactingcongress.org), or [www.senate.gov](http://www.senate.gov) and [www.house.gov](http://www.house.gov). For a list of public events in your area, [see the Town Hall Project](#).

### **NOTE:**

- **The 2020 Open Enrollment Period is November 1, 2019 to December 15, 2019.** See the [list of 2019 CMS Navigator grantees](#).
- [Get Ready: TRICARE Open Season, Federal Benefits Open Season Begins Nov. 11](#)

## UPCOMING WEBINARS AND CALLS

### **SERIES: [Health Reform: Beyond the Basics](#) (new webinars added)**

- [Part II: Premium Tax Credits](#)  
Thursday, October 3, 2019 | 2:00 pm ET
- [Part III: Auto-Renewal Process for 2020 on Healthcare.gov](#)  
Tuesday, October 8, 2019 | 2:00 pm ET
- [Part IV: Preventing & Resolving Data Matching Issues](#)  
Thursday, October 10, 2019 | 2:00 pm ET

- [Part V: Plan Design](#)  
Tuesday, October 15, 2019 | 2:00 pm ET
- [Part VI: Plan Selection Strategies](#)  
Thursday, October 17, 2019 | 2:00 pm ET
- **NEW** [Immigrant Eligibility for Health Coverage Programs](#)  
Tuesday, October 22, 2019 | 2:00 pm ET

**NEW** [Working with Immigrants: What Consumer Enrollment Assistance Providers Need to Know Now](#)

Tuesday, October 29, 2019 | 2:00 pm ET

**NEW** [Best Practices When Assisting People with Disabilities Enroll in Health Coverage](#)

Thursday, October 31, 2019 | 2:00 pm ET

- Series archive: [Part I: Determining Households & Income for PTC & Medicaid](#)  
Tuesday, October 1, 2019 | 2:00 pm ET

**NEW** [Get Ready for Seasonal and Pandemic Flu: Strategies for Early Care and Education Providers](#)

Tuesday, October 15, 2:00-3:30 ET

*National Center on Early Childhood Health and Wellness*

**NEW** [Addressing Health Disparities in the LGBTQ+ Community](#)

Wednesday, October 23, 12:30-2:00 ET

*The National Institute for Health Care Management (NIHCM) Foundation*

**NEW** [The Next Steps to Improving Home Health Care for Children with Medical Complexity](#)

Wednesday, October 23, 1:30-2:30 ET

*Lucile Packard Foundation for Children's Health*

[In addition to reading the suggested article -- [Home Health Care for Children with Medical Complexity: Workforce Gaps, Policy, And Future Directions](#) (Health Affairs, June 2019) -- see [Not Just Along For The Ride: Families Are The Engine That Drives Pediatric Home Health Care](#) (Health Affairs blog, 4/18/19).]

**NEW** [Medicare Basics](#)

Wednesday, October 30, 3:00-4:00 ET

*National Information & Referral Support Center (ADvancing States, formerly NASUAD)*

**NEW** [Best Practices When Assisting People with Disabilities Enroll in Health Coverage](#)

Thursday, October 31, 2:00 ET

*Center on Budget and Policy Priorities; presentation by the American Association on Health and Disability*

## **SERIES Person-Centered Planning and Practice**

*National Quality Forum/Administration for Community Living; Centers for Medicare and Medicaid Services*

- **Friday, December 13, 2019, 1:00-3:30 pm ET**
- **Monday, January 6, 2020, 1:00-3:30 pm ET**
- **Monday, February 3, 2020, 12:30-3:00 pm ET**
- **Monday, June 1, 2020, 1:00-3:30 pm ET**
- **[past] Friday, September 6, 2019**

## **THE COURTS**

**Court allows DOJ lawsuit over ‘fragile’ kids** ([News Service Of Florida](#), 9/19/19)

On September 17, a three-judge panel of a federal Court of Appeals overturned (on a 2-1 vote) a lower-court ruling that the Department of Justice (DOJ) did not have legal standing to sue the state of Florida regarding the placement of “medically fragile” children in nursing homes. As a result, the suit can move forward. The DOJ initially filed the suit in 2013, alleging that the state has violated the Americans with Disabilities Act.

## **CONGRESS**

### **Autism CARES Act Signed into Law**

The Autism CARES Act ([H.R.1058](#)), was [signed](#) into law on Monday, October 30. Among other things, the law:

- Authorizes programs at the National Institutes of Health (NIH); the Centers for Disease Control and Prevention (CDC); and the Health Resources and Services Administration (HRSA) through Fiscal Year 2024,
- Reauthorizes and expands the [Interagency Autism Coordinating Committee \(IACC\)](#), increasing from two to three members who are self-advocates, parents or legal guardians or represent advocacy/service organizations;
- Directs the Health and Human Services Secretary to prioritize grants to “rural and underserved areas;”
- Requires a comprehensive report to Congress on the demographic factors associated with the health and well-being of individuals with ASD and other developmental disabilities across the lifespan;
- Designates regional centers of excellence for ASD research and epidemiology;
- Directs activities to increase public awareness of autism, improve the ability of health providers to use evidence-based interventions, and increase early screening and detection;
- Authorizes \$50.6 million to the Health Resources and Services Administration (HRSA) for education, early detection, and intervention, and allows HRSA to prioritize new grant applicants in rural or underserved areas;
- Extends the [Leadership Education in Neurodevelopmental and Related Disabilities \(LEND\) programs](#), Developmental Behavioral Pediatrics (DBP) Training Programs, the “Learn the Signs. Act Early” campaign, and the Autism and Developmental Disabilities Monitoring (ADDM) Network.

The bill enjoyed bipartisan support in both houses of Congress, and had many more cosponsors than the 2014 legislation. Now that the Act has been reauthorized, funds must be appropriated to implement it.

## **Budget & Appropriations – Update**

October 1 marked the beginning of the federal 2020 fiscal year, but none of the 12 appropriations bills to fund government departments and agencies has yet been enacted. To keep the government operating, Congress and the president agreed to a “continuing resolution” (CR) to fund the government until November 21. The bills to fund the Departments of Labor, Health and Human Services (HHS), and Education have been developed in both the House and Senate. If each chamber passes its bill, a conference committee will have to resolve the differences, and the White House will have to agree to the final bill as well. (Administration officials are usually involved in the conference negotiations too.) As it was last year, funding for a wall on the southern US border may be an obstacle to final spending agreements.

## **Prescription Drug Prices**

As explained in the [September 25 Update](#), both Congress and the administration seem serious about addressing high prescription drug prices, but there are significant differences of opinion within Congress on how to do so. Moreover, the impeachment inquiry is likely to make it much more difficult for an agreement to be reached. See [Can Washington deliver on drug costs amid impeachment probe?](#) (Associated Press, 9/29/19) [Provides good overview of issues]; [Pelosi still hopes to work with Trump on drug bill despite impeachment inquiry](#) (CNBC, 9/25/19); [Impeachment push threatens to derail bipartisan efforts on health care costs](#) (The Hill, 09/25/19).

Background. House Speaker Nancy Pelosi (D-CA) developed [the House Democrats' version of drug-price legislation](#), the "Lower Drug Costs Now Act of 2019" ([H.R. 3](#) text; [summary](#)). See [Understanding The House Democrats' Drug Pricing Package](#) (Health Affairs Blog, 9/19/19). Under that bill, Medicare would annually negotiate prices for at least 25 brand-name drugs, tying the rates to costs in other developed countries. This is an approach that the president had suggested earlier. Nevertheless, Senate Majority Leader Mitch McConnell (R-KY) has said that the plan is “dead on arrival” in the Senate. See [McConnell Warns Pelosi's Drug-Pricing Plan Is DOA](#) (Politico, 9/19/19); [Trump claims he wants to lower drug prices. He'll have to convince his own party to do it.](#) (Vox, 9/23/19). Pharmaceutical companies are heavily lobbying and publicly advertising against this approach. An alternative approach was developed by Senate Finance Committee Chairman Chuck Grassley (R-IA) and Ranking Member Ron Wyden (D-OR). Their bill ([S. 2543](#)), approved by the committee (but not all Republicans) in July, would basically tie drug prices to the rate of inflation; drug makers that raise prices faster than inflation would have to pay the difference back to Medicare. See [Understanding The Senate Finance Committee's Drug Pricing Package](#) (Health Affairs Blog, 7/26/19).

## **Surprise Medical Bills**

As reported in the [September 25 Update](#), lawmakers seem serious about protecting consumers from surprise medical bills, but there are very different approaches on how to do so. Last week, the Congressional Budget Office came out with an estimate on an approach that is favored by doctors and hospitals – that it would increase the deficit by “double digit billions” of dollars. See [CBO: Fix backed by doctors for surprise medical bills would cost billions](#) (The Hill, 09/24/19). A different approach, favored by insurers, was adopted in House and Senate committees.

**Background.** In both the House and Senate, there are multiple bills on this issue. See [Comparing Federal Legislation on Surprise Billing](#) (To the Point, Commonwealth Fund blog, 9/19/19). As explained in a [blog post from the Bipartisan Policy Center](#), the Senate bill – which was reported out of the Committee on Health, Education, Labor & Pensions (HELP) in July -- would essentially tie out-of-network charges to a federal benchmark of median in-network rates for a geographic area. The House Energy & Commerce Committee bill, reported out of the Health Subcommittee -- would use that method with back-up arbitration between insurers and providers. In general, hospitals and doctors prefer an arbitration-only approach, while insurers prefer a benchmark approach. A good explanation of the issue can be found in [The Health 202: Doctors Are Gaining the Edge in Fight over Surprise Medical Billing](#) (Washington Post, 9/23/19).

**NEW:** The Georgetown University Center on Health Insurance Reforms (CHIR) has developed a resource for policymakers on this issue: [CHIR Launches New Resource Center for Policymakers on Surprise Medical Bills](#).

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

### **Final Rule on “Patients Over Paperwork” (regulation of health care providers)**

On September 26, the Centers for Medicare & Medicaid Services (CMS) issued a final rule (incorporating three proposed rules) -- the [Omnibus Burden Reduction \(Conditions of Participation\) Final Rule](#), which will go into effect on November 29, 2019. The rule is intended to reduce “paperwork” related to emergency preparedness, fire safety, and other regulations that apply to many types of health care facilities and providers, including hospitals, psychiatric hospitals, rural health centers, community health centers, long-term care facilities, ambulatory surgical centers, community mental health centers, outpatient rehabilitation facilities, hospices, portable X-ray services, and “religious nonmedical health care institutions.” The rule is summarized in a CMS [press release](#) and [fact sheet](#).

### **New Guidance on Qualified Residential Treatment Programs**

New guidance from the Centers for Medicare and Medicaid Services (CMS) -- [Qualified Residential Treatment Programs \(QRTP\) and Serious Mental Illness \(SMI\) and Serious Emotional Disturbance \(SED\) Demonstration Opportunity Technical Assistance Questions and Answers \(9/20/29\)](#) -- clarifies existing CMS policy regarding Institutions for Mental Diseases (IMDs) and its potential for impact on Qualified Residential Treatment Programs (QRTPs) defined in title IV-E of the Social Security Act (the Act) as amended by the Family First Prevention Services Act. CMS explains how states can provide Medicaid services to Medicaid-eligible children residing in these facilities.

### **[Federal Fiscal Year \(FFY\)18 Core Set Data Product Release](#)**

On September 26, the Center for Medicaid & CHIP Services (CMCS) released the FFY 2018 Child and Adult Core Set data and additional resources related to the quality of care provided under the Medicaid and CHIP programs. It includes information on 23 frequently reported child measures and 23 frequently reported adult measures voluntarily reported by states.

### **Report on Promoting Pediatric Health Equity in Medicaid**

The National Institute for Children’s Health Quality (NICHQ) has released a report, [Opportunities for Medicaid to Transform Pediatric Care for Young Children to Promote Health, Development, and Health Equity](#). This resource outlines specific framework for states and their partners—including clinicians,

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public health professionals, and advocates— to improve Medicaid for young children. As described by NICHQ, “The framework builds on science and best practices related to the ways child health practitioners and systems of care can provide more holistic, family-centered, and integrated care.”

### **Medical Transportation**

#### **[Uber And Lyft Ride-Sharing Services Hitch Onto Medicaid](#)**

(Kaiser Health News, 9/26/19)

**WORTH REPEATING:** The Children’s Hospital Association has developed a 10-minute online “learning module” to explain the basics of the Medicaid program - [Medicaid 101](#). It is available for anyone to use, and sharing is encouraged.

### **MEDICAID WAIVERS – TENNESSEE “BLOCK-GRANT” PROPOSAL**

**Worth Repeating:** As reported in the [September 18 Update](#), Tennessee has developed a waiver [proposal \(explanation, text, instructions for submitting comments\)](#) to change its method of federal Medicaid funding to a modified block grant. See [Tennessee Becomes First State with a Plan to Turn Medicaid into a Block Grant](#) (Washington Post, 9/17/19). **The state public-comment period is open through October 18.** After the proposal is submitted to the Centers for Medicare and Medicaid Services (CMS), there will be another public comment period.

Under block grants or per capita caps, there is a danger that a state will not have sufficient funds to cover all beneficiaries and/or services, particularly if a state suffers an economic downturn making more people eligible for Medicaid. The Centers for Medicare and Medicaid Services (CMS) has been developing guidance for states that would like to apply for waivers to receive their federal Medicaid payments as “block grants” or “per capita caps.” See [With Trump’s Blessing, Some States Aim to Cap Medicaid Rolls](#) (Pew Stateline, 7/24/19).

#### **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](#).

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

**NOTE: The 2020 Open Enrollment Period is November 1, 2019 to December 15, 2019.**  
[View a list of 2019 CMS Navigator grantees.](#)

#### **Community Outreach Collaboratives**

The National Disability Navigator Resource Collaborative (NDNRC) has funded eighteen [Community Outreach Collaboratives](#) (COCs) for the upcoming open-enrollment season – expanding on the eleven COCs that were funded in year two. The COCs have two primary tasks: 1) build cross-disability collaborations with other disability organizations; and 2) have the cross-disability collaboration work as a dissemination and outreach resource with their local and/or state navigators and assisters. The 18 COCs are (by HHS regions) are available at <https://nationaldisabilitynavigator.org/about/community-outreach-collaboratives/>.

## [CMS is Bringing Health Plan Quality Ratings to All Exchanges for the First Time](#)

(CMS News Release, 8/15/19):

For the first time, the Centers for Medicare & Medicaid Services (CMS) will require the display of the five-star Quality Rating System (or star ratings) available nationwide for health plans offered on the Health Insurance Marketplaces beginning with the 2020 Open Enrollment Period. Beginning with this year's Open Enrollment Period, consumers will be able to compare health coverage choices using a five-star quality rating of each plan on Marketplace websites, including [HealthCare.gov](#), similar to other CMS star rating programs, such as the Nursing Home Compare website. For more information see the fact sheet available at <https://www.cms.gov/newsroom/fact-sheets/health-insurance-exchange-quality-ratings-system-101>.

## TRICARE

### From TRICARE Benefits Updates:

#### [Make Vision Coverage Choices to Fit Your Needs](#)

Sept. 25, 2019

#### [Make Enrolling in TRICARE Easy With Beneficiary Web Enrollment](#)

Sept. 26, 2019

[Sign up for TRICARE email updates.](#)

Connect with TRICARE on [Facebook](#) and [Twitter](#).

## OTHER NEWS AND INFORMATION & RESOURCES

### [Statement on FDA efforts to encourage patient engagement in medical device clinical investigations](#)

On September 23, the Food & Drug Administration (FDA) released draft guidance on [Patient Engagement in the Design and Conduct of Medical Device Clinical Investigations](#). This draft guidance provides proposed recommendations for manufacturers to engage patients in multiple aspects of medical device clinical investigation design. The FDA has also created engagement mechanisms to provide timely input from patients on what it is like to live with their disease or condition and/or interface with a medical device. One such effort is the [Patient and Caregiver Connection](#) program, which establishes a formal process for FDA reviewers to engage with patients and patient organizations to obtain input on key issues when they are evaluating a medical device submission.

### **New Strategic Plan for the National Institute of Child Health and Human Development (NICHD)**

The NICHD released its new [strategic plan](#), which outlines research goals and priorities for the next five years. It presents the institute's research goals and objectives under five broad research themes: Understanding the Molecular, Cellular, and Structural Basis of Development; Promoting Gynecologic, Andrologic, and Reproductive Health; Setting the Foundation for Healthy Pregnancies and Lifelong Wellness; **Improving Child and Adolescent Health and the Transition to Adulthood; Advancing Safe and Effective Therapeutics and Devices for Pregnant and Lactating Women, Children, and People with Disabilities.** (Emphasis added.)

## NEW RESOURCES FROM AGENCIES AND PARTNERS:

From the Substance Abuse and Mental Health Services Administration (SAMHSA):

[Mental Illness and Substance Use in Young Adults](#)

From SAMHSA and CMS:

**New Updates from C2C's Roadmap to Behavioral Health**

The Centers for Medicare & Medicaid Services Office of Minority Health (CMS OMH), in partnership with Substance Abuse and Mental Health Services Administration (SAMHSA), has updated [The Roadmap to Behavioral Health](#). This *From Coverage to Care* (C2C) guide offers important information about mental health and substance use disorder services, finding a behavioral health provider, defining behavioral health terms, receiving services, and following up on care. It also includes links to other HHS services. To learn more or download C2C resources, visit [cms.gov/c2c](https://cms.gov/c2c) or email [CoverageToCare@cms.hhs.gov](mailto:CoverageToCare@cms.hhs.gov).

- To receive updates on *From Coverage to Care*? Subscribe to the [C2C listserv](#).
- Order printed copies of this publication from the [CMS Product Ordering Website](#).

From the Administration on Children and Families:

[Helping Community-Based Organizations Be Prepared for Emergencies](#) (re: people with disabilities and older adults)

From the Catalyst Center:

[State-by-State Resources for Families](#)

This directory, organized by state, provides links to a wide range of direct service organizations, and to important information related to Title V Maternal and Child Health programs. Title V programs work to improve the health and well-being of women and children, including children with special health care needs.

- **Worth Repeating:** [Helping Emergency Rooms Prepare for Kids in Crisis](#) (new HRSA toolkit)
- **Worth Repeating:** [CYSHCNet Develops Standards of Compensation for Family Partners in Research From Lucile Packard Foundation](#). The knowledge and experience of families and youth is invaluable to research about children with special health care needs (CSHCN), but family contributions have not been consistently recognized or compensated. CYSHCNet, a national research network founded in 2017, has developed [a standard of compensation for youth and family partners](#) (PDF) who participate on a research team, noting possible roles and responsibilities, as well as the type of support and compensation family members might expect. CYSHCNet also has created a companion piece, [a standard of compensation for research teams](#) (PDF) on how researchers can identify, orient, support, and compensate family and youth partners.



## YOUR INPUT SOUGHT

**Due October 31. HHS/NIH, *All of Us* Research Program:** [Request for Information \(RFI\) to Inform Tribal Collaborations](#). The *All of Us* research program seeks input on Tribal Nation issues and concerns, including the importance of proper handling of AI/AN biospecimens in accordance with Tribal beliefs and traditions, challenges with handling data from self-identified AI/AN individuals, and educating the research community on avoidance of stigmatizing research.

### FDA Patient Representatives

Are you a patient or caregiver who wants to get involved at FDA? Contact [the Patient Affairs Staff \(PAS\)](#) or follow them on Twitter [@FDAPatientInfo](#).

## OF POSSIBLE INTEREST

- [As off-label use spreads for lifesaving niche drugs, supplies grow scarce, leaving patients in the lurch](#) (Washington Post, 9/24/19)
- [Health Insurance Costs Surpass \\$20,000 Per Year, Hitting a Record](#) (Bloomberg, 9/25/19)
- [Leader's Perspective: What it Takes to Build a Family-First Children's Hospital](#): Drawing inspiration from other children's hospitals, one Florida facility redesigned various areas to be more patient and family-centered. (Children's Hospital Association, 9/7/19)
- [The 7 Things Families Care About Most](#): One hospital was surprised to learn that parents don't cite patient safety as being important, and there's a theory why. (Children's Hospital Association, 9/9/19)
- [How anti-vaxxers target grieving moms and turn them into crusaders](#) (NBC News, 9/24/19)

## SPECIAL ANNOUNCEMENTS

### Special Enrollment Period Available for Victims of 2019 Hurricane Dorian

Consumers who qualified for an another enrollment period, such as a special enrollment period (SEP) or Open Enrollment Period (OEP), but were unable to complete a Marketplace application, plan selection, or enrollment process due to Hurricane Dorian, may have access to an Exceptional Circumstances Special Enrollment Period (SEP). These individuals have 60 days from the end of the FEMA-designated incident period to complete their 2019 enrollment and request a retroactive start date based on when he or she would have picked a plan if not for Hurricane Dorian. Consumers will be considered "impacted" and eligible for this SEP if they reside, or resided at the time of the hurricane, in any of the [counties declared](#) as meeting the level of "individual assistance" or "public assistance" by the Federal Emergency Management Agency (FEMA). See [2018 guidance](#) on Special Enrollment Period (SEP) policy for consumers impacted by an emergency or major disaster. **Assisters, agents, and brokers can help affected consumers by contacting the Marketplace Call Center at 1-800-318-2596 or TTY at 1-855-889-4325 to request enrollment using this SEP.**

### **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. See the posters for general information and contact information: [general audience](#) and [youth audience](#).

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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Family Voices

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