



# FAMILY VOICES<sup>®</sup>

Washington DC Update  
September 12, 2018

## Greetings from Washington!

Both houses of Congress were on recess during the week of August 28, and returned after Labor Day. The biggest event in Congress since then has been the hearings on the confirmation of Brett Kavanaugh to join the Supreme Court. In other news, the Senate is poised to pass a bipartisan bill to address the opioid epidemic, and a House subcommittee approved a revised version of the ACE Kids Act, which would create health homes specifically for children with medically complex conditions. September is the last month of the 2018 federal fiscal year, so Congress is also working on appropriations bills.

September is also –

- [National Preparedness Month](#) for which numerous resources are available, including: [Children and Youth Preparedness Social Media Toolkit](#) and materials from the Centers for Disease Control and Prevention (CDC) focused on how to [Prepare Your Health - Emergency Preparedness: Including People with Disabilities](#); [Mission Possible: Preparing and Responding to Disasters through a Health Equity Lens](#); and [Ready to Respond to Public Health Emergencies](#).
- [National Sickle Cell Awareness Month](#)
- [Hispanic Heritage Month](#) (Sept. 15-Oct. 15)
- [National Childhood Obesity Awareness Month](#), and
- [Childhood Cancer Awareness Month 2018](#)

### **Important reminder for Certified Application Counselors and new applicants:**

This **Friday, SEPTEMBER 14**, is the deadline for all CDOs (Certified Application Counselor Designated Organizations) to submit an application to the CAC Program. Both **existing** CDOs and organizations that wish to become CDOs must apply. *(If you have already submitted a CDO application as part of the CDO Refresh this summer, and have your confirmation email from [cacquestions@cms.hhs.gov](mailto:cacquestions@cms.hhs.gov), you need not take further action.)* Existing CDOs that fail to submit their applications by Friday **will be de-designated and will not be permitted to certify CACs or assist consumers.** *Note: this application deadline is just to submit your application, not a deadline to be completely through the process. The CDO Application can be accessed [here](#).*

## UPCOMING WEBINARS AND CALLS

### **SERIES: HRSA Grants Education & Technical Assistance WEBINAR SERIES for Tribes, Tribal Organizations, Indian Health, Tribal, and Urban Indian Health Programs**

- **Wednesday, Sept. 12, 1:00-2:30 pm ET** – Effective Grants Management/Administration & Reporting
- **Wednesday, Oct. 10, 1:00-2:30 pm ET** – Successful HRSA Tribal Grantees: A Discussion on Best Practices, Lessons Learned in Managing HRSA Grants
- **Past: Preparing a Budget for Your Grant Proposal (Aug. 8)**

### **TODAY, NEW Crisis and Emergency Risk Communication (CERC): Spokesperson**

(Explains the critical role of an organization's spokesperson in an emergency.)

**Wednesday, Sept. 12, 2:00-3:00 pm ET**

*Centers for Disease Control and Prevention (CDC)*

**NEW SERIES:** As part of the Health Reform: Beyond the Basics project, the Center on Budget and Policy Priorities is presenting a four-part webinar series on **Core Elements of Eligibility and Enrollment under the Affordable Care Act**. For more information, visit

[www.healthreformbeyondthebasics.org](http://www.healthreformbeyondthebasics.org).

#### **Premium Tax Credits**

Thursday, September 13, 2:00-3:00 pm ET

#### **Determining Households and Income for PTC and Medicaid**

Tuesday, September 18, 2:00-3:00 pm ET

#### **Plan Design**

Thursday, September 20, 2:00-3:00 pm ET

#### **Plan Selection Strategies**

Tuesday, September 25, 2:00-3:00 pm ET

#### **Auto-Renewal Process in Healthcare.gov**

Thursday, September 27, 2:00-3:00 pm ET

### **Taking Action to Promote Health Equity – Lessons from The California Endowment's Building Healthy Communities Project**

**Tuesday, September 18, 1:30-3:00 pm ET**

*Trust for America's Health*

### **NEW Getting Health Insurance Coverage for Those with Mental Health and Autism Spectrum Disorder Treatments**

**Tuesday, September 18, 2:30-4:00 pm ET**

*Golden State Pooled Trust*

### **NEW Sickle Cell Transitional Care from Childhood to Adulthood: The Role of Community Health Workers**

**Thursday, Sept. 20, 1:00-2:00 pm ET**

*Office of Minority Health, U.S. Department of Health and Human Services*

**NEW Medical Necessity and EPSDT: Tools for Providers and Advocates**

Thursday, September 20, 1:00-2:30 pm ET

*American Academy of Pediatrics and the Georgetown University Center for Children and Families*

**A Conversation on Protecting Rights of Children with Medical Complexity in an Era of Spending Reduction**

Thursday, September 20, 2:00-3:00 pm ET

*Lucile Packard Foundation for Children's Health*

**NEW Creating Supportive Systems to Improve Mental Health Outcomes for Young African American Boys**

Thursday, September 20, 2:00-3:30 pm ET

*Substance Abuse and Mental Health Services Administration*

**NEW State Strategies to Meet the Needs of Children and Families Affected by the Opioid Crisis**

Thursday, Sept. 27, 2:00-3:00 pm ET

*National Academy for State Health Policy and the Alliance for Success*

**NEW ABLE Success in the Real World: Meet Three ABLE Account Owners and Hear Their ABLE Stories**

Thursday, September 27, 2:00-3:30 pm ET

*National Disability Institute*

**NEW Disability & Sexuality Part 3: Abuse Prevention & Empowerment**

Wednesday, October 10, 12:00-1:00 pm ET

*SPAN Parent Advocacy Network*

**NEW Using Kidsdata for Action**

Wednesday, October 24, 3:00-4:00 pm ET

*Family Voices of California*

**THE COURTS**

On September 5, a U.S. District Court judge in Texas held a hearing in the case of [Texas v. United States](#) (formerly [Texas v. Azar](#)), in which twenty Republican state attorneys-general are challenging the continued validity of the Affordable Care Act (ACA) now that the "individual mandate" for people to buy insurance has been repealed. The administration is not defending the law and is siding in part with the plaintiffs. The judge has not yet issued a ruling on the motion for a preliminary injunction. As explained in [Here's What You Need to Know About the Lawsuit Trying To End Obamacare](#) (ThinkProgress, 9/5/18), "Best case scenario: O'Connor lets the ACA stand or just strikes down the individual mandate, which is zeroed out in 2019 anyway. Worst case scenario: O'Connor grants the preliminary injunction, temporarily blocking enforcement of the entire ACA." For more detail, see

[Judge Hears Oral Arguments in Texas v. United States](#) (Health Affairs, 9/10/18). For information on how this might affect consumers, see [Lawsuit Threatens Affordable Care Act Preexisting Condition Protections But Impact Will Depend on Where You Live](#) (Commonwealth Fund blog, 8/29/18).

## CONGRESS

### Kavanaugh Hearings

The Senate Judiciary Committee held four days of hearings last week to consider the nomination of Judge Brett Kavanaugh to become an Associate Justice of the Supreme Court. He was questioned extensively regarding health care issues, particularly his positions on abortion rights and the Affordable Care Act. Since the [Texas v. United States](#) case challenging the constitutionality of the ACA (see above) could well wind up before the Supreme Court, his positions on issues raised in that case could determine the future of the law. As is the tradition among Supreme Court nominees, however, he refused to make any comments that would reveal how he might rule on specific issues.

The [last day of the hearings](#) was devoted to outside witnesses, among whom was Jackson Corbin, a 13-year-old with Noonan Syndrome, a disorder he shares with his brother and mother that affects multiple body systems. His moving written [testimony](#) was about the importance to his family of having insurance coverage despite their significant pre-existing conditions. Another witness was Liz Weintraub, of the Association of University Centers on Disability, who [testified](#) about the rights of people with disabilities like herself.

Confirmation of Judge Kavanaugh will take only a simple majority of Senators, so if all 51 Republicans vote “YES,” as currently expected, he will be confirmed. See [Kavanaugh Hearings Didn’t Alter Nominee’s Supreme Court Trajectory](#) (Washington Post, 9/9/18).

### ACE Kids Act

Last week the Subcommittee on Health of the House Committee on Energy and Commerce held a [hearing](#) and [approved](#) a [new version of the bipartisan ACE Kids Act](#), which would provide Medicaid reimbursement for states that choose to establish health homes for children with medically complex conditions, in order to better coordinate their care. The bill, sponsored by Rep. Joe Barton (R-TX) and Rep. Kathy Castor (D-FL), is a high priority for Rep. Barton, who is retiring from Congress at the end of the year. Family Voices and other children’s health organizations have been providing input to committee staff with the aim of ensuring that families would have a choice about whether their children will participate in a health-home program, among other things. There is a similar [companion bill in the Senate](#), which has been referred to the Finance Committee. An explanation of the bill can be found in the subcommittee [background memo](#) (p. 1-2). More information can be found on the [website of the Children’s Hospital Association](#), which has promoted the legislation.

### EMPOWER Act

Last week the Subcommittee on Health of the House Committee on Energy and Commerce held a [hearing](#) and [approved](#) a revised version of the “Ensuring Medicaid Provides Opportunities for Widespread Equity, Resources, and Care Act” or the “[EMPOWER Care Act](#).” The bill would reauthorize the Medicaid “Money Follows the Person” program, which helps people transition from institutional to

community-based care, and is strongly supported by the disabilities community. An explanation of the bill can be found in the subcommittee [background memo](#) (p. 2-3).

## **Opiod Legislation**

Last week Senators worked out a deal on legislation to address the opioid epidemic, and the compromise bill is expected to come to a vote as early as this week. Once it passes, there will be a House-Senate conference committee to negotiate a compromise between the Senate bill ([summary](#)) and the bill that passed the House in June. One significant difference between the bills – the House measure would allow some Medicaid reimbursement for treating adults in “Institutions for Mental Disease” (IMDs), while the Senate bill would not. Specifically, the House bill would lift the current “IMD exclusion” for up to 30 days of treatment per year, until 2023. See [The Health 202: Opioid Deal in Senate is Rare Bipartisan Win](#) (Washington Post, 9/7/18).

## **ACA Repeal Legislation?**

Former and now-again Senator Jon Kyl (R-AZ) was appointed by Arizona Governor Doug Ducey (R) to fill the vacancy left by the death of Senator John McCain. Senator Kyl has committed to holding the seat only until January 3, 2019 (the end of the current congressional session) but could hold the seat until a special election is held in 2020. In any case, he has said that he does not plan to run for reelection.

Unlike Senator McCain, Senator Kyl would be expected to vote in favor of legislation to repeal the Affordable Care Act (ACA). Since McCain cast the decisive third Republican “NO” vote to defeat earlier repeal legislation, Senator Kyl’s appointment has raised the question of whether Senate leadership might again bring up a bill to repeal the ACA. Senate Majority Leader Mitch McConnell (R-KY) has indicated that he does *not* plan to bring up such legislation before the November elections, but has not ruled out the possibility of doing so during the “lame-duck” session, after the election and before the beginning of the next session of Congress. Even if he does so, however, the new Democratic Senator from Alabama, Doug Jones, who took a previously Republican seat in a December special election, would be expected to oppose an ACA repeal bill, meaning that such legislation again would fail to pass the Senate if all other Democratic Senators continue to oppose repeal, as expected. See [McConnell: No Plan To Try Again On Obamacare Repeal Soon](#) (The Hill, 9/5/18).

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

### **Infographic: Medicaid and CYSHCN**

The Catalyst Center has created a one-page infographic illustrating important elements of Medicaid and children and youth with special health care needs (CYSHCN). This infographic is part of a series of infographics exploring key focus areas in the world of health care financing and coverage for CYSHCN. Resources for further exploration about family financial hardship are listed at the bottom of the infographic.

### **Updated State Medicaid and CHIP Snapshots**

The Georgetown University Center for Children and Families (CCF) and the American Academy of Pediatrics (AAP) created factsheets underscoring the importance of Medicaid in providing coverage for children in all 51 states (including the District of Columbia).

**[Exciting News: CMS Announces First Innovation Model Grants Aimed at Children and Youth](#)** (Say Ahhh! Blog of the Georgetown Center on Children and Families, 8/29/18)

**[Dismissal of Co-Chair of Iowa Medicaid Advisory Panel is Setback for Much Needed Oversight](#)** (Say Ahhh! Blog of the Georgetown Center on Children and Families, 9/6/18)

## **AFFORDABLE CARE ACT (ACA)**

### **WORTH REPEATING: Updated Advocate's Guide to MAGI**

The National Health Law Program has released an updated version of [The Advocate's Guide to MAGI](#) (Modified Adjusted Gross Income) methodologies used to determine financial eligibility for multiple insurance programs, including most Medicaid categories, the Children's Health Insurance Program (CHIP), and Premium Tax Credits and Cost Sharing Reductions for health plans purchased through the Affordable Care Act (ACA) Marketplaces.

## **TRICARE**

### **TRICARE Podcast, 9/7/18:**

#### **Child Enrollment in DEERS - ECHO - TRICARE for Life Overseas**

[Transcript](#) [Download](#)

*[Subscribe to get Podcasts via email](#)*

## **OTHER NEWS, INFORMATION**

### **WORTH REPEATING: MCHB Grand Challenges**

As reported earlier, the Maternal and Child Health Bureau will award four prizes in a [Grand Challenges](#) competition to develop innovative, low-cost, and scalable solutions to improve the health of mothers and children across the U.S. The [Care Coordination for CSHCN Challenge](#) page has been updated.

## **YOUR INPUT SOUGHT**

### **Survey on Attending Genetics Appointments after Referrals**

#### **Open until Oct. 12**

The NYMAC (New York-Mid-Atlantic Regional Genetics Network) -- one of seven regional networks in the country funded by the Health Resources and Services Administration -- is partnering with Family-to-Family Health Information Centers on a project to help understand why or why not people schedule and attend genetics appointments after a referral. The survey is open to any person or parent/guardian of a child who has ever been referred to a genetics professional, whether or not they scheduled or attended an appointment. Survey results will be used to create strategies to increase attendance to genetics appointments. The survey is completely voluntary and will take about 10-20 minutes to

complete. It is available in English and Spanish and is not limited to those living in the mid-Atlantic region. The survey can be taken online until October 12 [here](#).

**[CMS Tribal LTSS Program Survey](#)**

This survey is being conducted by the Centers for Medicare and Medicaid Services (CMS) to help them develop a list of tribally operated long-term services and supports (LTSS) programs across Indian Country. The results will enable the sharing of LTSS best practices across Indian Country. Tribes and tribal organizations may provide these services directly, or through a contract or agreement with an outside organization.

**Research Survey for Caretakers of Women with Intellectual and Developmental Disabilities**

A researcher at Brandeis University is conducting a study on sexual and reproductive health care for women with intellectual and developmental disabilities. She is seeking family caregivers of such women to complete an [online survey](#). The goal of the survey is to understand the perspectives and experiences of family caregivers about sexual and reproductive health care for women with intellectual and developmental disabilities.

**OF POSSIBLE INTEREST**

**[The Hidden Social Factors Driving Disparities in Childhood Cancer Survival Rates](#)**

Blog of the USC Annenberg Center for Health Journalism (8/21/18)

**[An Oasis of Compassion](#)**

As reported in *Penn Today*, since 2015, the Hospital of the University of Pennsylvania has supported the Family Caregiver Center—one of only a few in the United States.

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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! Comments and questions can be directed to [jguerney@familyvoices.org](mailto:jguerney@familyvoices.org).

Yours truly,  
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