



FAMILY VOICES[®]

Washington DC Update
September 19, 2018

Greetings from Washington!

Outside of the judicial-nomination realm, there has been a lot of bipartisan action in the Senate of late. On Monday, by vote of 99-1, the Senate approved a bill to address the opioid epidemic. That bill is on a fast track to be reconciled with opioid legislation passed by the House in June. Then, by a vote of 98-2, the Senate approved a bill to ensure that pharmacies can let patients know if they can get a lower price for their drugs if they do not use their insurance plan. On Tuesday, by a vote of 93-7, the Senate approved a bill reflecting a House-Senate conference agreement to fund the Department of Defense and the Departments of Labor, Health and Human Service and Education. In other news, the administration named a pediatrician with significant public health experience to be the new associate head of the Maternal and Child Health Bureau. Read about these issues and more in this week's Update.

Hurricane Florence: The Centers for Medicare and Medicaid Services (CMS) has announced a number of measures to help individuals, health care providers, and states affected by Hurricane Florence and its aftermath. See [CMS Continues Efforts to help with Hurricane Florence Emergency Response](#) and [CMS offers broad support for North Carolina and South Carolina with Hurricane Florence preparation](#).

Other government resources on disasters:

- The [CMS emergency webpage](#)
- The Centers for Disease Control and Prevention (CDC) [EPIC Alert - Be Safe from Hurricane Florence and Its Aftermath](#)
- The Substance Abuse and Mental Health Services Administration (SAMHSA) [Publications and Resources on Disaster Preparedness, Response, and Recovery](#)

September is –

- **[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](#)**

UPCOMING WEBINARS AND CALLS

Please note that several webinars listed below are taking place today, Wednesday, Sept. 19, and multiple webinars taking place on Thursday, Sept. 20, including several that are newly listed.

NEW National Preparedness Month: Children in Public Health Emergencies

Wednesday, September 19, 1:00 pm ET

Emergency Partners Information Connection (EPIC), Centers for Disease Control and Prevention

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

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

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

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

NEW The State of the Data on Hispanic Children and Families Webinar

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

National Research Center on Hispanic Children & 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

SERIES: As part of its *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.

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

Past: **Premium Tax Credits; Determining Households and Income for PTC and Medicaid**

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 EHDI (Early Hearing Detection and Intervention) & University Collaborations - Leveraging the Partnership to Enhance Program Implementation and Outcomes

Thursday, September 20, 3:00-4:00 pm ET

National Center for Hearing Assessment and Management, Utah State University

Live captioning will be provided; a link will be available for captioning upon logging into the webinar.

This webinar will be recorded and posted online at www.infanthearing.org

NEW Alternatives to Guardianship: Supported Decision Making

Tuesday, Sept. 25, 12:00-1:00 pm ET

The Parents Place of Maryland

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

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

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

- **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, Effective Grants Management/Administration & Reporting*

Disability & Sexuality Part 3: Abuse Prevention & Empowerment

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

SPAN Parent Advocacy Network

Using Kidsdata for Action

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

Family Voices of California

THE COURTS

New Suit Challenges “Short-Term, Limited-Duration” Plans

On September 14, several patient organizations filed suit in the D.C. Federal District Court to challenge the validity of the CMS regulation allowing the sale of “short-term, limited-duration” insurance policies. The plaintiffs are the Association for Community Affiliated Plans (nonprofit health plans); the National Alliance on Mental Illness; Mental Health America; the American Psychiatric Association.; AIDS United; the National Partnership for Women and Families; and Little Lobbyists. Among other things,

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they argue that the sale of these plans undermines the ACA's aims of ensuring that people with pre-existing conditions can obtain affordable health insurance and that insurance policies offer essential benefits. See [The New Lawsuit To Save Obamacare, Explained](#) (Vox, 9/14/18).

THE ADMINISTRATION

New Associate Head for the Maternal and Child Health Bureau

The administration has announced that Michael D. Warren, MD, MPH, FAAP, will become the Associate Administrator of the Health Resources and Services Administration's (HRSA's) Bureau of Maternal and Child Health, effective October 15, 2018. Dr. Warren is a board-certified pediatrician who currently serves as Deputy Commissioner for Population Health at the Tennessee Department of Health. In that role, he oversees the state's Title V Maternal and Child Health Services Block Grant Program. He has also served on the HHS Secretary's Advisory Committee on Infant Mortality and as president of the Association of Maternal and Child Health Programs (AMCHP). Laura Kavanagh, MPP, has been serving as the Acting Associate Administrator since October 2017.

CONGRESS

There is a lot of action on the Senate side of the Capitol at the moment...

Senate Opioid Legislation

On September 17, the Senate passed, by a vote of 99-1, legislation to address the opioid epidemic. (Senator Mike Lee, R-UT, was the "NO" vote.) The legislation was a compilation of bipartisan bills from five different committees. See the [statement](#) of Senator Lamar Alexander (R-TN), Chairman of the Committee on Health, Education, Labor, and Pensions (HELP) or the more detailed (20 pp.) [section-by-section summary](#) of the bill. Among several provisions related to infants, children, and adolescents, the Senate bill would increase the authorization level for the National Child Traumatic Stress Initiative. The [House passed](#) a large opioid bill in June ([summary](#)). Unlike the Senate bill, the House bill would temporarily lift the current-law ban on Medicaid reimbursement for treatment of adults in "institutions for mental disease" for those with an opioid-use disorder. The House bill also includes a provision easing privacy restrictions so that families and others can see patient records under certain circumstances. See [Senate Passes Massive Legislation to Combat Opioid Crisis](#) (Washington Examiner, 9/17/18) Now, a House-Senate conference committee is meeting to resolve the differences between two bills, with the aim of sending it to the president's desk before the midterm elections. See [What's In, What's Out, and What's Still on the Table in the Opioids Package Passed by the Senate](#) (Stat, 9/17/18).

Appropriations

On September 18, the Senate passed a bill reflecting a House-Senate conference agreement to provide FY 2019 appropriations for the Department of Defense and the Departments of Labor, Health and Human Services, and Education. The bill (H.R. 6157) was approved by a vote of 93-7. See the statement of Senate Appropriations Committee Chairman Richard Shelby (R-AL), [Senate Passes Final Defense, Labor-HHS-Education Appropriations Minibus Conference Report](#). The conference bill includes a \$2 billion increase for the National Institutes of Health, and an increase of \$206 million (to \$3.8 billion) to combat the opioid crisis. It also includes increases for several other programs of interest:

- An increase of \$26 million for the “Special Programs of Regional and National Significance” (SPRANS) portion of the MCH Block Grant. The increase is allocated to specific maternal-health initiatives. Although the MCH block grant to states was level-funded, the increase in funding for the maternal-health initiatives will free up any block-grant funds that states had been spending on these activities.
- \$10 million for a new CDC initiative to support collaboration with state, tribal, territorial, and local health departments to monitor mothers and babies impacted by Zika virus during pregnancy in the highest-risk areas, and to pilot, in additional jurisdictions, the Zika surveillance/registry system to capture data on Zika and other emerging public health threats to mothers and babies, such as opioid use during pregnancy, natural disasters, and pandemic influenza.
- \$300,000 to establish and carry out the activities of the Family Caregiving Advisory Council created by the RAISE Family Caregivers Act.

The conference report must still pass both chambers of Congress, which is expected, and be signed into law by the President. The bill text, conference committee’s “joint explanatory report,” and summaries of the bill can be found on the [website](#) of the House Committee on Appropriations.

Senate Bill on Pharmacy “Gag Clauses”

By a vote of 98-2, the Senate passed legislation to ban pharmacy "gag clauses," so that pharmacists are not prohibited from telling customers that they can save money on prescriptions by paying with cash instead of insurance. Such gag clauses are sometimes included in contracts between pharmacies and insurers or pharmacy benefit managers. President Trump had tweeted his support for the measure. See [Senate Passes Massive Opioid Package, Bill To Ban Gag Clauses](#) (Fierce Healthcare, 9/18/18). A similar bill was marked up in the House Energy and Commerce Committee on September 7.

Bipartisan Senate Measure on “Surprise Medical Bills”

The Hill newspaper [reports](#) that a bipartisan group of Senators has developed a [draft measure](#) to crack down on surprise medical charges from providers outside an insurance plan’s network. The bill would: prevent an out-of-network from charging additional costs for emergency services; require health care providers to give written notification to patients who receive emergency care at an out-of-network facility before they receive any follow-up nonemergency care; and prohibit charges from out-of-network doctors at an in-network hospital (such as an anesthesiologist or emergency physician). See [Bipartisan Senators Unveil Proposal to Crack Down on Surprise Medical Bills](#) (The Hill, 9/18/18).

Kavanaugh Hearings

WORTH REPEATING: As reported in [last week’s Update](#), the Senate Judiciary Committee’s initial hearings on Supreme Court nominee Brett Kavanaugh included several outside witnesses. Among them was Jackson Corbin, a 13-year-old with Noonan Syndrome, a rare disorder he shares with his brother and mother and which 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. **NEW:** You can watch Jackson’s testimony [here](#), beginning at about minute 30:35. Another witness, Liz Weintraub of the Association of University Centers on Disability, [testified](#) about the rights of people with disabilities like herself.

MEDICAID AND CHIP NEWS, INFORMATION AND RESOURCES

[Health Coverage Matters for Children: The Role of Medicaid in the Healthy Development of America's Children](#) (New Issue Brief from Families USA: Sept. 2018)

WORTH REPEATING: [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.

WORTH REPEATING: [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).

Medicaid Waivers

[A Snapshot of State Proposals to Implement Medicaid Work Requirements Nationwide](#) (National Academy for State Health Policy, updated 9/14/18)

AFFORDABLE CARE ACT (ACA)

Navigator Grants

On September 12, the administration [announced](#) the award of \$10 million (total) for 39 grants for “Navigators,” which help consumers select ACA health plans in states with federally-facilitated Exchanges. The total amount awarded reflects a decrease of 84 percent in Navigator funding since 2016. Three states (IA, MT, and NH) will have no federally-funded Navigators. See a state-by-state [list of the Navigator awardees](#). CMS has also announced the commencement of [Navigator training](#).

TRICARE

[WORTH REPEATING: Podcast: Child Enrollment in DEERS - ECHO - TRICARE for Life Overseas](#)

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

[Subscribe to get Podcasts via email](#)

OTHER NEWS, INFORMATION AND RESOURCES

Inappropriate Psychotropic Medication for Foster Children

A recent report from the Office of the Inspector General, US Department of Health and Human Services (HHS), reveals that many children in foster care are inappropriately receiving psychotropic medications, while other children are not receiving the medications they need. See the report:

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[Treatment Planning and Medication Monitoring Were Lacking for Children in Foster Care Receiving Psychotropic Medication](#) (U.S. Department of Health and Human Services Office of Inspector General, Sept. 2018). See also [Watchdog Slams Safeguards for Foster Kids on Psych Drugs](#) (Associated Press, 9/17/18).

Care Coordination for Children with Medical Complexity – Q&A

On July 26, the Lucile Packard Foundation for Children’s Health held a webinar, "Conversation on Care Coordination for Children with Medical Complexity: Whose Care Is It, Anyway?" Now available are responses to questions that were submitted during the webinar but were not answered in the allotted time. [Read the Q&A.](#)

National Standards for Systems of Care for Children and Youth with Special Health Care Needs

The Association of Maternal & Child Health Programs (AMCHP) and the National Academy for State Health Policy (NASHP), with funding from the Lucile Packard Foundation for Children’s Health, have developed [National Standards for Systems of Care for Children and Youth with Special Health Care Needs \(CYSHCN\)](#) to define the core components of a comprehensive, coordinated, and family-centered system of care for CYSHCN. This interactive toolkit provides a portal to tools, fact sheets, and other resources that **states** can use to design, strengthen, and improve health care systems serving CYSHCN and their families.

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](#) proposals are **due October 30.**

YOUR INPUT SOUGHT

[Listed in order of due date, if applicable.]

NEW: Seeking Parent Input on What Doctors Should Know in Caring for Children

The Council on Medical Student Education in Pediatrics is revising its General Pediatric Clerkship Curriculum. The foundation includes **“The skills, attitudes, and knowledge that every doctor must know and do to safely and compassionately care for children.”** The Council is asking for YOUR INPUT AS A PARENT WHO HAS INTERACTED WITH PHYSICIANS CARING FOR CHILDREN on what you feel are the crucial components ANY PHYSICIAN needs to know to care for children. It will take approximately 5 minutes to complete the survey, [COMSEP - Family input on Curriculum](#).

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.

ANNOUNCEMENT

Pediatricians Partnering with Parents to Promote Social and Emotional Development of Children, Birth to Age 3

The National Institute for Children’s Health Quality (NICHQ) is seeking applications from **primary care family and pediatric practices** who provide well-child visits to children, birth to age 3 who are interested in joining the [Pediatrics Supporting Parents Learning Community](#). Participating practices will test and implement tools and changes aimed at supporting families as they support the social and emotional development of their children. Practices will collaborate with colleagues across the country during a 17-month learning community launching January 2019. All participating practices will receive a stipend to support their involvement. Learn more on the [Pediatrics Supporting Parents](#) website. If you have any questions, please connect with the NICHQ team at psp@nichq.org.

OF POSSIBLE INTEREST

[Behind the Scenes: Working to Pass Federal Maternal Mortality Legislation](#) (From AMCHP’s *Pulse* 9/13/18) – This is a great description of parts of the legislative process.

[Children Lose Out on Liver Transplants, Study Finds](#) (NBC News, 9/17/18)

[Breaking New Ground: Supporting Employed Family Caregivers with Workplace Leave](#) (AARP Public Policy Institute, 9/4/18)

[When ICE Comes Knocking, Healthcare Workers Want to Be Prepared](#) (Healthcare Dive 9/15/18)

[Shifting Non-Emergency Medical Transportation to Lyft Improves Patient Experience and Lowers Costs](#) (Health Affairs blog, 9/14/18)

[Childhood Trauma and Its Lifelong Health Effects More Prevalent Among Minorities](#) (National Public Radio, 9/17/18)

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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! Comments and questions can be directed to jguerney@familyvoices.org.

Yours truly,
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Director of Public Policy
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