



FAMILY VOICES[®]

Washington DC Update
July 12, 2017

Did you know that ONE in FIVE families has at least one child with special health care needs? [Join the Family Voices One-in-Five Awareness Campaign.](#)

Greetings from Washington! The drama still continues... Just before the 4th of July congressional recess, Senate Majority Leader Mitch McConnell (R-KY) postponed the vote on the “Better Care Reconciliation Act,” the Senate’s version of legislation to “repeal and replace” the Affordable Care Act (ACA). An amended version of the bill is expected to be released Thursday. At this point, it doesn’t seem that the bill could pass the Senate, **but** the outcome is still very uncertain. In other news, the FDA has approved the first new drug for the treatment of sickle cell disease in about 20 years. Read about these issues and more below.

UPCOMING WEBINARS AND CALLS

[How Medicaid and CHIP Shield Children from the High and Rising Costs of Prescription Drugs](#)

Friday, July 14, 2:00 pm ET

Sponsored by the Georgetown Center on Children and Families

[Supporting Title V and Medicaid Collaboration in Pediatric Medical Home Implementation](#)

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

Sponsored by the National Center for Medical Home Implementation, the National Academy for State Health Policy and the Catalyst Center

THE ADMINISTRATION

Surgeon General

At the end of June, President Trump [nominated](#) Jerome Adams, MD, MPH, to be the next Surgeon-General of the United States. Adams, an anesthesiologist, currently serves as the Indiana Commissioner of Health. In that position, he handled an AIDS/HIV outbreak in the state and was able to establish a needle exchange program to address it. See [Trump’s Surgeon General Pick Built Name Fighting HIV and Opioids in Indiana.](#)

New CDC Director

Secretary of Health and Human Services Tom Price, MD, has named [Brenda Fitzgerald, MD](#) to be the next Director of the Centers for Disease Control and Prevention (CDC) and Administrator of the Agency for Toxic Substances and Disease Registry (ATSDR). Dr. Fitzgerald, an obstetrician-gynecologist, has

been serving as commissioner of the Georgia Department of Public Health and state health officer for the past six years.

Nominee for Assistant Secretary for Mental Health and Substance Abuse

On June 15, the President submitted to the Senate his [nomination](#) for Assistant Secretary for Mental Health and Substance Use -- Elinore McCance-Katz, PhD, MD. McCance-Katz previously served as the first chief medical officer at SAMHSA, then worked in the same role at the Rhode Island Department of Behavioral Health. She must be approved by the Senate Committee on Health Education, Labor and Pensions (HELP).

CONGRESS

Health Care Legislation - Update

The [June 30 Update](#) provided an explanation of the Senate version of legislation to “repeal and replace” the Affordable Care Act (ACA), the “Better Care Reconciliation Act” (BCRA). After a Congressional Budget Office (CBO) [analysis](#) of the bill concluded that it would result in 22 million more uninsured individuals by 2026 compared to current law, Senate Majority Leader Mitch McConnell (R-KY), cancelled a vote he had planned to hold on the bill before the Independence Day recess.

As leadership had feared, Senators faced widespread constituent opposition to the bill during that recess. There are currently [11 Republican Senators](#) who have said they oppose the bill *in its current form* – Senators Collins (ME), Murkowski (AK), Capito (WV), Moran (KS), Heller (NV), Hoeven (ND), Portman (OH), Johnson (WI), Paul (KY), Lee (UT), and Cruz (TX). (The last three believe it should go further in repealing the ACA; the others are concerned primarily about Medicaid cuts.)

Senate leadership plans to release two amended versions of the bill on Thursday -- one including an [insurance provision](#) sought by Senators Cruz (R-TX) and Lee (R-UT), and one without it. The CBO score of the Cruz-Lee provision, expected next week, will help to determine whether the bill ultimately will include it.

[Reportedly](#), the amended bill will not make any significant changes in the Medicaid provisions; it would still subject Medicaid to per capita caps, although it may have the slightly higher inflation factor included in the House bill. There are rumors that the amended bill will make some changes to the “carve-out” (from the Medicaid caps) for children who are blind or disabled (see the [June 30 Washington Update](#)), perhaps to more precisely define or expand the protected group. Analysts say that this [carve-out will not really protect the most vulnerable children](#) from the negative impact of the caps, however. See also [Millions of Kids Fall Outside Senate Plan To Shield Disabled from Medicaid Cuts](#) (Kaiser Health News, July 10, 2017).

A vote on the bill may take place as early as the end of next week. All Democrats oppose it. Since there are 52 Republicans in the Senate and Vice-President Pence can break a tie, the bill will fail if three or more Republican Senators vote against it. Significantly, Senator [Shelley Moore Capito \(R-WV\) has said](#) that she is willing to cast the vote that kills the bill if it comes to that.

The [outlook at this point is uncertain](#). Although it will be difficult for Senator McConnell to accommodate both ends of his party's spectrum, he is known to be a good negotiator, so it is possible that he will be able to get the bill passed.

If the bill fails or is never brought to the Floor for a vote due to lack of support, then McConnell has said he may reach out to Democrats to develop legislation to stabilize the insurance marketplaces. In fact, the [Democratic leadership wrote a letter](#) to McConnell this week, urging him to work with them on such legislation. See [Republicans debate Plan B if ObamaCare repeal fails](#).

ACA NEWS, INFORMATION AND RESOURCES

[Lots of Changes for 2018 Marketplace Enrollment Mean Confusion for Consumers](#) (Georgetown Center on Health Insurance Reforms blog post, June 21)

OTHER NEWS, INFORMATION AND RESOURCES

FDA Approves New Drug to Treat Sickle Cell Disease

Last week the FDA approved a new drug to reduce the complications associated with sickle cell disease. The drug, Endari, made by Emmaus Medical, is the first new treatment for sickle cell disease to secure FDA approval in almost 20 years. As [reported in STAT](#), however, Endari's active ingredient - L-glutamine -- is an old chemical that can be purchased over the counter, which could complicate Emmaus's ability to obtain insurance coverage. In the manufacturer's clinical trial, treatment with Endari over 48 weeks reduced the frequency and length of hospital visits for sickle cell pain crises compared to a placebo.

Emergency Treatment of Those with Sickle Cell Disease

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is sharing steps to improve care in emergency departments (ED) of hospitals and clinics for people with sickle cell disease (SCD). According to the NCBDDD, SCD patients often experience [barriers to timely care](#) in the ED. To address these problems, the NCBDDD has released two fact sheets -- one for those with SCD and another for emergency healthcare workers -- about ways to improve healthcare in the ED for patients with SCD. The Center request that these [fact sheets](#), plus its [blog post](#), and other [information about SCD](#) be shared widely.

Faulty Blood Lead-Level Tests

The U.S. Food and Drug Administration (FDA) and the CDC have [warned](#) that certain lead tests manufactured by Magellan Diagnostics may produce inaccurately low results. Parents of children younger than six years old, pregnant women, and nursing others who have been tested for lead exposure are recommended to contact a health care professional to see if they should be retested. CDC recommendations for health care providers to retest children younger than six years of age if:

- the lead test was conducted with any Magellan Diagnostics' LeadCare System tests using blood drawn from a vein;
- they received a result of less than 10 micrograms per deciliter ($\mu\text{g}/\text{dL}$)

Balance Billing Protections

[Balance Billing by Health Care Providers: Assessing Consumer Protections across States](#) (The Commonwealth Fund); [synopsis](#) in Georgetown Center on Health Insurance Reforms blog post, June 20)

Tool to Measure Family Experience of Care Integration

The family perception of care integration is essential in identifying opportunities to improve care coordination and care management. The Pediatric Integrated Care Survey (PICS), a validated instrument from Boston Children's Hospital that assesses family experience of care integration, was introduced at a June 15 webinar. The webinar provided an overview of the tool, and highlighted how one hospital is using it to make improvements. See the [recording and presentation slides](#) and the speakers' [responses](#) to questions.

New Resources for Parents of Children Who Are Deaf or Hard of Hearing

Hear to Learn (www.heartolearn.org), a program of the Utah State University Department of Communicative Disorders and Deaf Education and the National Center for Hearing Assessment and Management (NCHAM), offers user-friendly materials for parents, caregivers, teachers, and other professionals in both English and Spanish.

Materials include downloadable activities that focus on language, literacy, math and music, and video tutorials on hearing loss and hearing device management (additional tutorials are planned on topics related to language learning, academics, and family well-being). The website also offers a place where families can share their stories, ask an expert, and log on to webinars.

SignIt (www.infanthearing.org/signit/) is an online beginning American Sign Language (ASL) course with 10 units that teach beginning conversational ASL (vocabulary, sentences, grammar and syntax) and Deaf culture. The self-paced curriculum is estimated to take 25–30 hours to complete. The curriculum is free to parents of birth to 36-month-old children who are deaf or hard hearing ages 0–3. Visit the NCHAM website to complete and submit a form (www.infanthearing.org/signit/).

Transition Resources for Practices

Got Transition has developed a [new tip sheet](#) (PDF) to assist practices that are looking for resources to obtain certification on transition from the National Committee on Quality Assurance Patient-Centered Medical Home. [Got Transition](#)'s goal is to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

Well-Visit Planner - CAHMI and Help Me Grow Center Partnership

The [Child and Adolescent Health Measurement Initiative](#) (CAHMI) has entered a partnership with the [Help Me Grow](#) (HMG) National Center. In this partnership, the CAHMI will leverage its [Well-Visit Planner](#) (WVP) to provide support for HMG affiliate sites to engage families, communities, and child health providers in promoting children's healthy development. The Well Visit Planner is an online pre-visit planning and education tool (based on the American Academy of Pediatrics' Bright Futures guidelines) that promotes family engagement and helps parents of children ages four months to six years learn about and plan for their child's next preventive care visit. For more information on how your organization or practice can implement the [Well-Visit Planner](#) and CAHMI's [Cycle of Engagement](#), please contact Kara Skelton at kskelton@cahmi.org.

YOUR INPUT SOUGHT

The **American Indian and Alaska Native Health Research Advisory Council** (HRAC) is requesting nominations for the following areas: Alaska, Albuquerque, Bemidji, Billings, California, Great Plains, Nashville, Navajo, Oklahoma City, Phoenix, Portland, Tucson, and National-at-Large. Deadline is July 15, 2017. <https://www.minorityhealth.hhs.gov/hrac/>

Mental Health Services for Youth

Do you work with youth or young adults with mental health needs?

Research is showing that youth with mental health needs in the transition years are in need of individualized, developmentally appropriate, culturally responsive, and empowerment-oriented services. Staff at the [Research and Training Center for Pathways to Positive Futures](#) has joined with [Youth MOVE National](#) to design and conduct *Supporting You in Supporting Youth: A [Survey on Training Needs](#) of Transition Age Youth Service Providers*. The survey should take about 10 minutes to complete.



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!

And, as always, please feel free to contact us with any questions. Comments and questions can be directed to jguerney@familyvoices.org.

Yours truly,
The Family Voices Policy Team

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