



FAMILY VOICES[®]

Washington DC Update
July 3, 2018

Greetings from Washington! Last week was a busy one in Congress, the courts, and the administration. The House rejected an immigration bill, and a Senate committee approved some maternal and child health bills. One federal court ordered the administration to stop separating children from their families, and another federal court invalidated a Medicaid waiver. The administration rejected a Medicaid waiver, and issued several Medicaid bulletins. Read about all these developments in this week's Update.

UPCOMING WEBINARS AND CALLS

(All topics; in chronological order, by first webinar in a series where applicable.)

[Leveraging Digital Tools to Treat Patients along the Continuum of Care](#)

Wednesday, July 11, 2:00-3:00 ET

FierceHealthCare/Appian (one presenter is from Nemours Children's Hospital)

[Adverse Childhood Experiences: Implications for Policymakers and Practitioners](#)

Wednesday, July 11, 4:00-5:00 ET

[The Dibble Institute](#)

NEW [Assistive Technology Resources for Family Caregivers and Respite Care Providers Announced](#)

Thursday, July 12, 2:00-3:00 ET

The AT3 Technical Assistance and Training Center

NEW [Where the Magic Happens: A Guide to Grassroots Organizing for Consumer-Driven Delivery Reform!](#)

Thursday, July 12, 2:00-3:00 ET

Community Catalyst Center for Consumer Engagement in Health Innovation

To learn about the guide, [Where the Magic Happens: A Guide to Grassroots Organizing for Consumer-Driven Delivery Reform!](#)

NEW [Putting Medicaid to Work](#)

Tuesday, July 17, 1:00-2:00 ET

USC Annenberg Center for Health Journalism

Save the Date: EPSDT Education for Providers and Advocates

Wednesday, July 18, 1:00-2:30 ET

Registration details to be announced later

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[Cannabidiol \(CBD\) Use in Pediatric Treatment-Resistant Epilepsy](#)

Thursday, July 19, 3:00-4:00 ET

Family Voices of California

THE COURTS

Federal Court Invalidates Approval of Kentucky Waiver to Establish Medicaid Work Requirements

The state of Kentucky requested a waiver from the Centers for Medicare and Medicaid Services (CMS) to impose work requirements on Medicaid beneficiaries. CMS approved the state's request. On June 29, the Federal District Court for the District of Columbia invalidated the waiver approval, however. See [Federal Judge Blocks Kentucky's Medicaid Work Requirements](#) (Vox, 6/29/18). The court did **not** declare that work requirements can never be established as a condition of Medicaid eligibility. Rather, the court's ruling was based on the fact that the administration failed to consider a "salient factor" in deciding to grant a waiver – the waiver's impact on furnishing medical assistance. The Secretary's failure to consider this factor rendered his decision "arbitrary and capricious" (a common legal basis for invalidating federal regulations). See [Medicaid Work Requirements: Inside The Decision Overturning Kentucky HEALTH's Approval](#) (Health Affairs blog, 7/2/18). The ruling directly affects only Kentucky's waiver, and the decision can be appealed by the administration. CMS Administrator Seema Verma [said](#) that the agency will be conferring with the Department of Justice to consider next steps.

On July 2, Kentucky Governor Matt Bevin (R) announced that he would be canceling dental and vision benefits for the "able-bodied" adults who became eligible for Medicaid under the expansion allowed by the Affordable Care Act (the "expansion" population), unless they earn the benefits. See [Bevin Cuts Dental, Vision Benefits To Nearly 500K Medicaid Recipients](#) (Louisville Courier Journal, 7/2/18). This is the population on which he sought to institute work requirements.

THE ADMINISTRATION

Family Separations at the Border

The Department of Health and Human Services (HHS) Office of Refugee Resettlement (ORR) has custody of over 2000 children who were separated from their parents after crossing the border illegally since May. The president issued an [Executive Order](#) on June 20 to end the practice of separating children and their families. See [The Executive Order Trump Claims Will End Family Separation, Explained](#) (Vox, 6/21/18). T

The exact procedures by which children will be reunited with their families are still not clear, however. The Department of Homeland Security issued a bulletin on June 23 -- [Fact Sheet: Zero-Tolerance Prosecution and Family Reunification](#) – which outlines some of the steps, and reportedly the administration has created an "[unaccompanied children reunification task force](#)" to carry out the reunification process. See also [Trump Will Reunite Separated Families — But Only If They Agree to Deportation](#) (Vox, 6/25/18).

Democrats in the House and Senate have called for committee hearings, and Rep. Frank Pallone (D-NJ) has [asked](#) the Government Accountability Office to investigate the administration's reunification efforts. On June 29, Energy & Commerce Committee Republicans sent a [letter](#) to the Department of

Health and Human Services (HHS) regarding its Office of Refugee Resettlement (ORR) and the management, treatment, and reunification of unaccompanied alien children. The [HHS Inspector General will be investigating](#) the health and safety conditions at the agency's shelters for unaccompanied migrant children.

On June 26, a [federal court ordered the reunification of families](#). See also [Trump Administration Says It Won't Return Children to Immigrant Parents in Custody, But a Judge Orders Families Be Reunited](#) (Los Angeles Times, 6/26/18)

On June 27, the House failed to pass an immigration bill. (See below.)

Here are some reports about the potential health-related consequences of the family-separation policy:

- [10-Year-Old Migrant Girl With Down Syndrome Separated From Family: Report](#) (The Hill, 6/19/18)
- [Doctors Say Migrant Children Separated From Their Parents Will Face Lasting Ills](#) (Politico, 6/26/18)
- [Key Health Implications of Separation of Families at the Border \(as of June 27, 2018\)](#) (Kaiser Family Foundation, 6/27/18)
- [Immigrant Families Placed In Detention Centers Face Health Care Challenges](#) (Kaiser Health News, 7/2/18)

A related article: [Fearing Deportation, Immigrant Parents Are Opting out of Health Benefits for Kids](#) (Kaiser Health News, 6/26/18)

White House Proposed Government Reorganization

As reported in last week's Update, the White House has revealed a [plan](#) to reorganize and merge several departments of the federal government. See the [White House Fact Sheet](#). Not mentioned last week: part of this reorganization plan would be to reduce the Public Health Service Commissioned Corps by about 40 percent, from 6500 to 4000, and to create a Reserve Public Health Corps to be deployed during emergencies. See [White House Wants to Cut This Public Health Service Corps by Nearly 40 Percent](#) (Washington Post, 6/27/18).

CONGRESS

Immigration Legislation

On June 27 the House voted on immigration legislation that would have provided funding for a border wall, addressed the separation of immigrant families, and provided a path to citizenship for the so-called DREAMers (young adults who were brought to the country illegally as children). The bill was soundly rejected, by a broader margin than had been expected by leadership ([301 to 121](#)). All Democrats voted no, as did nearly half of the Republicans – those who preferred a more conservative bill. See [House Rejects Immigration Bill Pushed by Trump in Last-Minute Tweet](#) (Washington Post, 6/27/18).

Opioid Legislation

On June 21, the House approved the Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities Act – or [SUPPORT for Patients and Communities Act](#) (H.R. 6) – which consolidated multiple previously passed bills. See [What’s in The House’s Bills to Address the Opioid Crisis — And What’s Not](#) (Stat, 6/21/18). The Senate has not yet considered separate opioid bills approved by the Senate Committee on Health, Education, Labor, and Pensions (HELP) and Senate Finance Committee. See also [Federal Legislative Proposals Related to Medicaid and Opioids: What to Watch](#) (Kaiser Family Foundation, 7/2/18).

Maternal and Child Health Legislation

On June 26, the Senate Committee on Health, Education, Labor and Pensions (HELP) approved two bills intended to improve maternal and child health. The [Maternal Health Accountability Act](#) (S. 1112) would establish a new grant program administered by CDC to provide funding to states to establish or sustain statewide maternal mortality review committees, among other things. The [PREEMIE Reauthorization Act](#) (S. 3029) would renew current legislation that supports CDC research and data collection on premature births and reauthorizes programs at the Health Resources and Services Administration aimed at improving the treatment and outcomes of infants born prematurely.

FY 2019 Appropriations

Update: The Senate Appropriations Subcommittee on Labor, HHS, and Education approved its version of the bill to fund those agencies in FY 2019, and the full committee approved the bill the next day. (See the [committee report](#).) As reported in last week’s Update, the corresponding House subcommittee marked up its version of the bill earlier. (See this [summary](#) of maternal and child health provisions prepared by the Association of Maternal and Child Health Programs.) The full committee in the House will take up the bill sometime after this week’s recess.

MEDICAID AND CHIP NEWS, INFORMATION AND RESOURCES

CMS Rejects Massachusetts Request to Restrict Medicaid Drug Formulary

The Massachusetts Medicaid program asked the Centers for Medicare and Medicaid Services (CMS) to waive several different requirements of Medicaid law pursuant to the federal government’s waiver authority granted in section 1115 of the Social Security Act. Among the state’s proposals was one to strictly limit the prescription drugs covered by Medicaid. Numerous patient groups [opposed](#) the state’s proposal. CMS denied the state’s request, without a clear rationale, but suggested it would consider letting the state restrict its drug formulary if the state waived Medicaid drug rebates and instead negotiated prices directly with drug manufacturers. See the [CMS letter](#), page 2. See the [press release](#) from the Cancer Action Network commending the decision to deny the Massachusetts’s request.

Informational Bulletin on Medicaid Home and Community-based Services

As [announced](#) on June 28, the Centers for Medicare & Medicaid Services (CMS) released an [Informational Bulletin](#) on ensuring the health and welfare of individuals receiving Medicaid-funded Home and Community Based Services (HCBS). The Centers for Medicaid & CHIP Services (CMCS) Informational Bulletin follows up on a joint report issued in January 2018 by the Office of Inspector General, the Office of Civil Rights, and the Administration for Community Living, focusing on individuals with developmental disabilities living in group homes. The Informational Bulletin addresses one of the three suggestions in the Joint Report: to encourage states to implement compliance oversight programs for group homes and regularly report to CMS.

CMS announces initiatives to strengthen Medicaid program integrity

On June 26, CMS [announced](#) ways that it would seek to strengthen program integrity. See [CMS Launches Slate of Initiatives Aimed at Curbing Fraud, Waste in Medicaid](#) (FierceHealthcare, 6/26/18).

CMS Guidance on Medicaid Coverage of Drugs Approved by the FDA under Its “Accelerated Approval Pathway”

On June 27, the Centers for Medicare & Medicaid Services (CMS), Center for Medicaid and CHIP Services (CMCS) released guidance to states through [State Release #185](#), titled *State Medicaid Coverage of Drugs Approved by the FDA under Accelerated Approval Pathway*. The release specifies that a drug approved by the Food and Drug Administration (FDA) under its “accelerated approval” pathway, must be covered by state Medicaid programs if the drug meets

YOUR INPUT SOUGHT

[Listed in order of due date.]

Traveling by Air with Service Animals [corrected from May 31 Update.]

Comments due July 9

On May 23, the Department of Transportation (DOT) published an [Advanced Notice of Proposed Rulemaking \(ANPRM\)](#) regarding regulations of service animals under the Air Carrier Access Act (ACAA). The Department simultaneously issued an [Interim Statement of Enforcement Office Priorities](#) about how it plans to target enforcement of the Act with respect to service animals in airplane cabins until the regulations are revised. According to the Statement: “Airlines are expected to continue to comply with the existing service animal requirement which allows U.S. airlines to deny transport only to certain unusual service animals such as snakes, other reptiles, ferrets, rodents, and spiders.” The Department is accepting public comments on the ANPRM, and has specifically asked for feedback on [ten questions](#) related to topics such as documentation required by passengers, leash/harness requirements, and how to safely transport large service animals. The comments are due **on July 9**, and can be submitted [here](#).

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. The survey is available [here](#).

OF POSSIBLE INTEREST

[Teaching Parents of Kids with Disabilities to Fight Back](#) (NPR, 6/29/18, text and audio) – story about the Partners in Policymaking program.

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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!

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

Yours truly,
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Family Voices

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