



# FAMILY VOICES<sup>®</sup>

Washington DC Update  
August 9, 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 over health care legislation continued until the last minute, when Senator McCain joined Senators Collins and Murkowski in opposing the so-called “skinny bill” to repeal parts of the Affordable Care Act, thereby ending consideration of health care legislation, at least before Congress’ month-long August recess. Before leaving town, the Senate passed a bill on the regulation of prescription drugs, which included a “right-to-try” provision and a provision intended to increase the number of cancer drugs for children. Meanwhile, child health organizations are speaking out about the need to extend funding for the Children’s Health Insurance Program (CHIP), which just turned 20 but for which funding expires on September 30. Read about these issues and more in this week’s Update.

**Please note:** Given the congressional recess, there will not be another Washington Update until September 13<sup>th</sup>. Any time-sensitive information will be sent in individual emails.

## **Registration Open for Family Voices National Leadership Conference**

Family Voices' 2017 leadership conference will be held in November in Washington, DC, bringing together Family-to-Family Health Information Centers, Family Voices State Affiliate Organizations, other family-led organizations and family leaders, and professional stakeholders. The theme is "Weaving a Tapestry of Strength Through Diversity," and early-bird registration is now available. [Read more and register.](#)

## **UPCOMING WEBINARS AND CALLS**

### **[#ABLEtoSave Series: ABLE Eligibility and Interplay with Public Benefits](#)**

**Wednesday, August 9, 2:00 pm ET**

Sponsored by the National Disability Institute and the ABLE National Resource Center

Other upcoming webinars in this series:

- Week 3 (August 13 - 19): Qualified Disability Expenses
- Week 4 (August 20 - 26): Financial Literacy
- Week 5 (August 27 - September 2): Enrollment

To learn more about the #ABLEtoSave campaign and ABLE accounts, visit the ANRC [website](#) and be sure to "like" the ANRC on [Facebook](#) and Twitter ([@theABLENRC](#)).

### **[Normal Pressure Hydrocephalus: Treatments and Current Research](#)**

**Wednesday, August 9, 7:00-8:00 pm ET**

Sponsored by the Hydrocephalus Association

## [Introduction to the National Family Support Network's Parent Advisory Committee Training and the Standards of Quality for Family Strengthening and Support](#)

**Wednesday, August 16, 12:30-1:30 pm ET**

Sponsored by the National Family Support Network

## [Mental Health Parity: Ensuring Equal Access to Treatment for Children and Youth in California](#)

**Wednesday, August 16, 3:00 - 4:00 pm ET**

Sponsored by Family Voices of California

## [Advancing Health Equity in Tribal Communities through Public Health Accreditation](#)

**Thursday, August 24, 3:00 - 4:00 pm ET**

Sponsored by the National Partnership for Action to End Health Disparities

## **THE ADMINISTRATION**

Since many of the details of the Affordable Care Act were developed by regulation, they can be changed by regulation. Changes in formal regulations require a notice-and-comment period, but there are other actions (or inactions) that can be undertaken more quickly. See [Unexpected Defeat of Repeal Bill Doesn't Mean End of Threats to ACA Health Coverage](#) (Georgetown Center on Children and Families "Say Ahhh!" blog post, July 31, 2017). The president has said he wants to let "Obamacare" "implode," and the administration can exacerbate potential problems toward that end. Most notably, the administration can choose not to continue "cost-sharing-reduction" (CSR) payments to insurance companies. These payments reimburse insurers for the cost of selling plans with reduced deductibles and copayments. Insurers are required to sell such plans to individual with incomes below 400 percent of the federal poverty level. The Obama administration made these payments, but its authority to do so was challenged in a lawsuit brought by the Republican-controlled House of Representatives. The [lawsuit is ongoing](#).

President Trump has continued the CSR payments, but has threatened to stop them, which would almost certainly [cause insurers to raise premiums](#) or pull out of the Exchanges. To some extent, this has already happened due to the uncertainty about future CSR payments. Insurers participating in the federal Marketplace must submit any final adjustments to their proposed 2018 rate requests by August 16, but they may not yet be certain whether they will receive future CSR payments. (The next monthly payment is due on August 21.) State insurance commissioners, who approve or deny the premium increases, are [in a quandary](#) about what to do if the CSR payments are not ensured. By September 27, insurers must sign contracts if they want to participate in the federal exchange for plan year 2018. See [3 key dates in the battle over Obamacare's subsidies](#) (CNN Money, Aug. 3, 2017). One of the actions that Congress might take to ensure stability of the individual insurance market is to provide mandatory funding for future CSR payments.

## **CONGRESS**

### **Health Care Legislation**

**What happened?** As outlined in earlier Updates, the Senate version of a bill to "repeal and replace" the Affordable Care Act (ACA) has gone through many changes intended to attract the votes of enough Senators to pass it. On July 25, there was a "Motion to Proceed" to take up the House-passed bill. All

Democrats and two Republicans (out of 52) - Senators Lisa Murkowski (R-AK) and Susan Collins (R-ME) - voted no, meaning there was a tie. Vice-President Pence was on hand to break the tie (the only situation in which the vice-president can vote in the Senate). Thus, the House bill, the American Health Care Act (H.R. 1628) was taken up by the Senate.

Three major amendments “in the nature of a substitute” were offered to the bill. One – the “ObamaCare Repeal Reconciliation Act” (ORRA), promoted by Sen. Rand Paul (R-KY) – would have repealed key parts of the ACA, effective in two years, without any replacement. That [amendment was defeated](#) by a vote of 45-55. (Seven Republicans joined all Democrats in opposition.) The second substitute amendment was a version of Sen. McConnell’s Better Care Reconciliation Act (BCRA). Among other things, that substitute amendment would have repealed or amended key parts of the ACA, (e.g., eliminating the individual and employer mandates, phasing out the Medicaid expansion, and reducing premium subsidies), and it would have capped and cut federal Medicaid payments to states. According to the nonpartisan [Congressional Budget Office](#) (CBO), an earlier version of that bill would cause 15 million more people to be uninsured in 2018, compared to current law, 19 million more in 2020, and 22 million more in 2026. A vote on that substitute amendment failed by a vote of 43-57. Nine Republican Senators joined all Democrats in opposition.

**The “skinny bill.”** After the defeat of these substitute amendments and various smaller amendments, a vote on the final bill was scheduled to take place late on Thursday, July 27. At that point, Senator McConnell offered the final substitute amendment – the so-called “[skinny bill](#).” Among other things, this amendment would have eliminated the ACA’s individual mandate; temporarily eliminated the employer mandate and a medical device tax; eliminated about a billion dollars in funding for the Centers for Disease Control and Prevention; prevented certain clinics (primarily Planned Parenthood clinics) from getting Medicaid reimbursement for one year; increased funding for community health centers; allowed greater contributions to Health Savings Accounts; and made it easier for states to waive certain provisions of the ACA. The “skinny bill” did *not* include any caps or cuts to the Medicaid program.

The “skinny bill” amendment was intended only to get legislation through the Senate so that it could negotiate a compromise bill with the House, either in a formal “conference committee” or on an informal basis. The “skinny bill” was not necessarily considered desirable policy. In fact, several Senators, including John McCain (R-AZ), announced in a press conference that they would vote for this amendment only if the Speaker of the House, Paul Ryan (R-WI), provided assurances that the House would *not* pass the Senate bill without amending it. Speaker Ryan provided assurance that the House would negotiate with the Senate to craft a compromise bill, but he did not promise that he would never bring the Senate-passed “skinny bill” to a House vote.

**The climax.** Voting on the “skinny bill” amendment started in the wee hours of Friday morning. Senators Collins and Murkowski voted against it, meaning one more “no” votes would keep it from being adopted. At about 1:29 AM (ET) Friday, Senator McCain entered the Senate chamber. After getting the attention of the clerk, he gave a thumbs-down signal ([video](#)), killing the amendment. (All other Republicans voted for the amendment, so the final vote was 49-51.) Since there was no other path by which to get a bill out of the Senate, the defeat of the amendment effectively killed the bill. After this vote, Majority Leader McConnell withdrew the bill from consideration.

**What’s next?** Many people have assumed that the failure of the Senate to pass a health bill means the end of efforts to repeal and replace the ACA, but this is not necessarily the case. The administration and some Senators and Representatives are urging that the legislation be re-visited. Some House and

Senate Republicans, [led by Rep. Mark Meadows](#) (R-NC), are working on an alternative bill intended to get the 51 votes needed to pass the Senate. Senators Bill Cassidy (R-LA) and Lindsay Graham (R-SC) are pushing a [proposal to give states block grants](#) roughly equivalent to the funds the states would get from ACA subsidies and a capped Medicaid program. Under this plan, states would have very few restrictions or requirements from the federal government.

Other members of Congress, however, are seeking a bipartisan approach to addressing some of the immediate problems with the individual health insurance market – mainly the increase in premiums and the [total absence or limited choice](#) of insurance plans in many areas for those buying through the Exchanges. The most urgent and important measure to address these problems would be enactment of a law to ensure continuation of cost-sharing-reduction payments to insurance companies. (See “The Administration” section above.) Other measures could be taken to ensure that everyone can purchase an insurance plan. See [Fixing Our Most Pressing Health Insurance Problems: A Bipartisan Path Forward](#) (Tim Jost, in “To the Point,” The Commonwealth Fund, July 13, 2017); and [If They Really Want to Stabilize the ACA Markets](#) (Axios, Aug. 2, 2017).

The Chairman and Ranking Minority Member of the Senate Health, Education, Labor and Pensions (HELP) Committee – Senators Lamar Alexander (R-TN) and Patty Murray (D-WA), respectively – are trying to craft a bipartisan bill, although [they face many obstacles](#). Chairman Alexander has announced that he will hold hearings in September about how to stabilize the health insurance markets. In addition, about 40 centrist members of the House and Senate have been meeting privately for months as the “Problem Solvers Caucus,” and have developed some [principles to stabilize the market](#).

Many consumer and provider groups, including [Family Voices](#) and a [coalition of patient organizations](#), are urging Congress to undertake a bipartisan approach to solving current problems with the health care system.

## OTHER LEGISLATIVE NEWS

### “Right-to-Try” Bill Includes Pediatric-Cancer Drug Provision

Shortly before adjourning last week, the Senate [approved a "right to try" bill](#) sponsored by Senators Ron Johnson (R-WI) and Joe Donnelly (D-IN). If enacted the legislation would give terminally ill patients the right to access drugs not yet approved by the Food and Drug Administration (FDA). The House and president must approve the bill before it becomes law. The bill also includes a provision designed to increase the number of approved pediatric cancer treatments by giving the agency authority to direct pharmaceutical companies developing oncology drugs for adults to test them in children as well. See [Senate Passes “Right to Try” Bill to Help Terminally Ill Patients Get Experimental Drugs](#) (Washington Post, Aug. 3, 2017).

### CHIP Funding

The Children’s Health Insurance Program (CHIP) celebrated its 20<sup>th</sup> [birthday](#) on August 5. Although the program is authorized through FY 2019, it is funded only through FY 2017, which ends on September 30, 2017. Child health advocates, including Family Voices, have been urging Congress to extend the authorization and funding for CHIP for another five years (through FY 2022). The Medicaid and CHIP Payment and Access Commission (MACPAC), a congressional advisory commission [has recommended the same](#). Ideally, a funding extension would have been enacted earlier this year, so that state legislatures and governors could prepare state budgets accordingly, and services could continue without interruption. States can spend any unspent funds past the end of the fiscal year, but at this point, some states are so close to running out of their CHIP funds that they will be required to send out

termination notices to enrollees soon, and their ability to negotiate contracts with providers and vendors will be hampered. Colorado has already [announced](#) that it will freeze enrollment and re-enrollment as of October 1. MACPAC has [projected when each state will run out of funds](#). The [program enjoys bipartisan support](#), but it is unclear when Congress will take up the CHIP legislation, and whether it will get caught up in other issues. A hearing on CHIP has been scheduled for early September in the Senate Finance Committee.

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

### **Promoting Access in Medicaid and CHIP Managed Care**

On July 31, the Center for Medicaid and CHIP Services issued an [Informational Bulletin](#), announcing the availability of a toolkit developed by a working group of states, [Promoting Access in Medicaid and CHIP Managed Care: A Toolkit for Ensuring Provider Network Adequacy and Service Availability](#), which provides guidance and resources to help states fulfill their responsibilities to ensure access to care for Medicaid and CHIP beneficiaries enrolled in managed care plans.

### **Special Needs Trusts**

On August 2, the Centers for Medicare & Medicaid Services (CMS) issued a [State Medicaid Directors Letter \(SMDL # 17-001\)](#) to provide guidance to states on the implications of section 5007 of the 21st Century Cures Act (the “Cures Act”), Pub. L. No. 114-255, “Fairness in Medicaid Supplemental Needs Trusts.” This provision permits individuals with disabilities to set up a special needs trust on their own behalf, rather than having to rely on a third party to do so. Special needs trusts generally permit individuals living with disabilities who are under age 65 to set aside assets to meet their needs without impacting their eligibility for Medicaid.

### **GOP states move to cut Medicaid**

The Secretary of Health and Human Services (HHS), former Representative Tom Price (R-GA), and the head of the Centers for Medicare and Medicaid services, Seema Verma, both believe states should have greater flexibility in administering their Medicaid programs, as outlined in a [letter issued to states](#) in March 2017. As [reported in The Hill](#), at least six states with Republican governors— Arkansas, Kentucky, Arizona, Maine, Wisconsin and Indiana —are seeking approval from HHS to alter requirements for Medicaid eligibility, such as work requirements, drug testing, premiums, time-limits and more restrictive income thresholds. If the administration approves such requirements for some states, it is expected that others will follow suit. The Secretary has great discretion in granting waivers, but, if approved, some of these changes may engender legal challenges.

### **WORTH REPEATING: Medicaid Coverage of Drugs and Services Provided to Blood Disorder Patients**

On June 30, the Centers for Medicare & Medicaid Services (CMS) issued [State Release #182](#) providing guidance on Medicaid coverage of drugs and services provided to blood disorder patients.

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

### **2018 Assister Certification Bulletin Now Available**

CMS has released the [2018 Assister Certification Bulletin](#), which outlines the Navigator and certified application counselor (CAC) certification and recertification requirements for the 2018 plan year, including the certification training curriculum for the Federally-facilitated Marketplace (FFM). In this

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bulletin, the updated training curriculum is referred to as the “2018 training.” The 2018 training is available through the Marketplace Learning Management System (MLMS) and can be accessed through the CMS Enterprise Portal by logging in or registering as a new user at <https://portal.cms.gov/wps/portal/unauthportal/registration>. Existing users can login at: <https://portal.cms.gov>.

## **OTHER NEWS, INFORMATION AND RESOURCES**

### **WORTH REPEATING: [TRICARE Expands Treatment Options for Mental Health and Substance Use Disorders](#)**

TRICARE expanded [mental health and substance use disorder \(SUD\) services](#), adding [intensive outpatient programs](#) and expanding options for [opioid treatment](#). In addition to other improvements, this expansion improves access to care and increases opportunities for mental health and SUD treatment. It also makes it easier for beneficiaries to access the right level of care for their health and wellness needs.

## **OF POSSIBLE INTEREST**

### **[NICU Experience: Questions from Parents of Babies with Spina Bifida](#)**

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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](mailto:jguerney@familyvoices.org).

Yours truly,  
The Family Voices Policy Team

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