



# FAMILY VOICES<sup>®</sup>

Washington DC Update  
October 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.](#)

As [recognized by President Trump](#), October is **Down Syndrome Awareness Month**.

**Greetings from Washington!** The latest development in the health policy world was the approval of CHIP bills by the Senate Finance Committee and the House Energy and Commerce Committee. The latter also approved a bill to extend funding for Family-to-Family Health Information Centers (F2Fs). (More details below.) Senators continue to work on potential bipartisan bill to stabilize the individual health insurance market, and the administration has made some decisions that may result in fewer people enrolling in health plans during the open enrollment period beginning on November 1.

## **Hurricane-Related Information:**

- The Centers for Medicare and Medicaid Services (CMS) established new special enrollment periods for people affected by recent natural disasters. (See below.)
- The Substance Abuse and Mental Health Services Administration (SAMHSA) is offering a [Disaster Distress Helpline](#) available by calling **1-800-985-5990** or texting **TalkWithUs** to **66746**.
- The Centers for Disease Control and Prevention (CDC) has various resources available at [Returning Home after a Disaster: Be Healthy and Safe](#), and [Prevent Injury after a Disaster](#).
- The Georgetown Center on Health Insurance Reforms [answers questions about access to health care and insurance benefits after a disaster](#).

## **Registration Open for Family Voices National Leadership Conference #FVLeadership2017**

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.](#)

[PLEASE NOTE: There will be no Washington Update next week.]

## **UPCOMING WEBINARS AND CALLS (ALL TOPICS)**

### **[Preventing and Resolving Data-Matching Issues](#)**

**Wednesday, October 18, 2:00-3:00 pm ET**

Sponsored by the Center on Budget and Policy Priorities

### [Zika Virus and Your Eyes](#)

**Wednesday, October 18, 2:30-3:30 pm ET**

Sponsored by the Focus Initiation, Prevent Blindness

### [Paid Family and Medical Leave from the Disability Angle](#)

**Monday, October 23, 2:00-3:00 pm ET**

Sponsored by The Arc

### [The Development and Validation of an Assessment of Youth/Young Adult Voice in Agency-Level Advising and Decision Making](#)

**Tuesday, October 24, 1:00-2:00 pm ET**

Sponsored by Youth MOVE National

### [Positive Psychology, Mindfulness, and Prevention in Children's Mental Health](#)

**Thursday, October 26, 12:00-1:00 pm ET**

Sponsored by National Federation of Families for Children's Mental Health

### [Exploring a Community-based Peer-to-peer Approach to Mental Health and Wellness](#)

**Friday, October 27, 10:30-11:00 am ET**

Sponsored by the Vermont Family Network

### [Communicating With Your Kids: Sexuality And Developmental Disabilities](#)

**Wednesday, November 1, 3:00-4:00 pm ET**

Sponsored by Family Voices of California

## **THE ADMINISTRATION**

### **2018 OPEN ENROLLMENT (Nov. 1 through Dec. 15, 2017)**

#### **Special Enrollment Periods (SEPs) for Those Affected by Recent Hurricanes**

The Centers for Medicare and Medicaid Services (CMS) has [announced](#) that individuals who live in (or move from) areas affected by one of the recent hurricanes will be eligible for an SEP that extends open enrollment for 2018 coverage through December 31, 2017 (instead of December 15). This special enrollment period also will apply to individuals who experienced a special enrollment period qualifying event between 60 days prior to the start date of the incident period and December 31, 2017, but were unable to complete the application, plan selection, and enrollment process due to a hurricane-related weather event in 2017. **Individuals affected by the storms may contact the Exchange Call Center at 1-800-318-2596 to enroll in a plan.**

There will also be an SEP for Medicare, which can be arranged by calling 1-800-MEDICARE.

#### **Federal open enrollment changes**

The open-enrollment period for obtaining 2018 insurance coverage through the *federal* Exchange will occur for six weeks, from November 1 through December 15, 2017. This is shorter than earlier (12-week) open-enrollment periods. As reported in the [September 20 Update](#), the administration has also

reduced the budget for advertising open enrollment and for [funding the Navigators](#) who provide assistance to consumers. As a result, many [Navigator grantees will cut their services](#), especially in rural areas, according to a recent [survey](#) conducted by the Kaiser Family Foundation. In addition, the administration [announced](#) that it will have maintenance shut-downs of the HealthCare.gov website for 12 hours (from midnight to 12 pm ET) every Sunday during the open-enrollment period except on December 10. As a result, the website will be available 93 percent of this year's open enrollment compared to [99.99 percent of the time in the two previous open-enrollment periods](#). Some consumer [advocates are concerned](#) that the reduced open-enrollment period (with maintenance closures, effectively 42 days instead of the former 90) will reduce the number of enrollees and yield a higher percentage of enrollees who have health problems, thus causing an increase in premiums.

## OPEN ENROLLMENT RESOURCES

### For Assisters:

CMS' [From Coverage to Care \(C2C\)](#) website has a number of resources for both consumers and those assisting them in securing and using health care coverage. Its updated [Enrollment Toolkit](#) reflects 2018 figures, and is available to download or print. The toolkit has 5 sections, addressing why consumers should sign up for health coverage, what to know before enrolling, what to know when picking a plan, what to do after enrollment, and information for special circumstances. [Immigrant Eligibility for Coverage Programs](#) (webinar slides and recording from Health Reform: Beyond the Basics, Center for Budget and Policy Priorities)

### For Families:

The [From Coverage to Care \(C2C\)](#) website includes a number of resources for consumers about how to use their insurance coverage to get the care they need. One of these resources, [Manage Your Health Care Costs](#), helps families plan for the costs associated with health coverage. To learn more or download C2C resources, go to on the C2C website at <https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/C2C-Enrollment-Toolkit-2016-small-508.pdf> or email [CoverageToCare@cms.hhs.gov](mailto:CoverageToCare@cms.hhs.gov).

## Executive order on association plans to be sold across state lines?

The president has said that he plans to issue an executive order, possibly this week, that would allow insurance purchasers to form associations for the purpose of buying group insurance. Such [association plans could be sold across state lines](#) and might not be required to meet ACA standards. If this is the case, the plans would be less expensive, attracting healthier people, thus resulting in a less healthy pool of individuals enrolled in more robust ACA plans, [in turn making those plans more expensive](#). Such an executive order would [likely be subject to lawsuits](#) challenging the president's authority to make these changes by executive order. The National Academy for State Health Policy has done a [report](#) on issues related to selling policies across state lines.

## CONGRESS

### ACA-RELATED LEGISLATION

**“Repeal and Replace.”** As you know by now, the Senate never voted on the legislation proposed by Senators Lindsey Graham (R-SC) and Bill Cassidy (R-LA) that would have provided block grants to states to help their residents get private insurance and would have cut and capped federal Medicaid payments. (See the [September 20 Washington Update](#) for more details about the bill.) In addition to all 48 Democrats, Republican Senators Rand Paul (KY), John McCain (AZ), and Susan Collins (ME) announced that they would oppose the legislation. Senator Lisa Murkowski (R-AK), who had opposed an earlier repeal-and-replace bill, [indicated](#) that she would not have been comfortable voting for the bill without more complete information on how it would affect her constituents, but she did not rule out voting for such legislation in the future.

Senators Graham and Cassidy have said they [would like to continue their efforts](#) to get their bill, or a similar one, enacted. But [some other Republicans seem to think](#) repeal-and-replace legislation is not viable. Meanwhile, the [president said](#) recently that he had reached out to Senate Minority Leader Chuck Schumer (D-NY) to see if he could work with Democrats on health care legislation. And speaking of bipartisan efforts...

**Bipartisan Bill on Insurance-Market Stabilization and CSR Payments.** As noted in an earlier Update, Senate Health, Education, Labor and Pensions (HELP) Committee Chairman Lamar Alexander (R-TN) and Ranking Member Patty Murray (D-WA), who have a history of working together, have been negotiating on legislation to stabilize the individual health insurance market in order to keep premiums in check and to ensure that plans are available in all markets. One issue in the negotiations is the length of time to ensure reimbursement to insurance companies for the "cost-sharing reductions" (CSRs) they are mandated to provide low-income families. Without assurances of these payments, insurers may drop out of the individual-insurance marketplace or raise premiums substantially. It has been reported that Chairman Alexander is willing to guarantee these payment for two years (rather than the one year he first proposed), but he trying to get Democrats to agree to give states more flexibility in plan design and to allow the sale of lower cost “copper” plans in the exchanges. Even if Senators Alexander and Murray can reach an agreement, [it is unclear](#) that they will be able to sell it to the Senate at large, the House, and the president.

### CHIP Funding (updated)

On October 4, both the Senate Finance Committee and the House Energy and Commerce Committee approved legislation to extend funding for the Children’s Health Insurance Program (CHIP) for an additional five years (through 2022). Both bills would also:

- Extend the current 23-percentage-point “bump” in the CHIP matching rate through FY 2019, phasing down to 11.5 percentage points in FY 2020 and then reverting to the regular CHIP matching rate in FYs 2021 and 2022; and
- Extend the CHIP [maintenance-of-effort \(MOE\) requirements](#) for children in families with annual income less than 300% of the federal poverty level for three additional years (FYs 2020-2022). Under current law, the MOE applies through FY 2019 to children in families with income less than 400% of the poverty level, but [most CHIP enrollees are in the below-300% group anyway](#).

For more details on the CHIP bill, including its provisions relating to Medicaid funds for Puerto Rico and the Virgin Islands, see the [October 6 special edition of the Washington Update](#).

The Energy and Commerce Committee's bill was approved along party lines. Although Democrats agreed with the bill's policies, they opposed the bill's "offsets" to pay for its cost. Among other offsets, the CHIP bill would change Medicaid third-party-liability rules in a manner that would jeopardize reimbursement for prenatal care and pediatric preventive services. Recently, however, House Energy and Commerce Committee Chairman Greg Walden (R-OR), said that [he would hold off in trying to advance the CHIP bill through the House](#) in order to negotiate with the Democrats on offsets.

The Senate Finance Committee approved its bipartisan bill on a voice vote with no dissent. That bill did not include any offsets, but before it advances to the full Senate, leaders will most likely identify offsets to cover the cost of extending CHIP funding.

Federal CHIP funding expired on September 30. States have varying amounts of remaining funds to support the program for a few more months or more, but before their funds run out they will have to notify enrollees about potential termination of eligibility. See [States Say They Will Run Out of CHIP Funds Faster than Projected; Will Congress Act in Time?](#) (Georgetown Center on Children and Families, 9/28/17).

## **F2F FUNDING**

On October 4, the House Energy and Commerce Committee approved a bill - the "Community Health And Medical Professionals Improve Our Nation," or [CHAMPION Act](#) (H.R. 3922) - which included a provision to extend funding for Family-to-Family Health Information Centers (F2Fs). The bill would extend funding for Family-to-Family Health Information Centers (F2Fs) for two more years (FYs 2018 and 2019) at \$6 million per year (an increase of \$1 million per year), *AND* calls for F2Fs to be developed in all territories and for at least one Indian tribe. (See [bill section 104](#).) The territories are Puerto Rico, Guam, American Samoa, the Virgin Islands, and the Northern Mariana Islands.

The CHAMPION Act also extends funding for Community Health Centers, the Special Diabetes Programs, the National Health Service Corps, Teaching Health Center Graduate Medical Education, the Youth Empowerment Program, and the Personal Responsibility Education Program.

Although the committee Democrats agree with the policies in the CHAMPION Act, they all voted against it due to their objection to the offset – a cut in the Prevention and Public Health Fund created by the Affordable Care Act (ACA). The Prevention Fund is used, among other things, to pay for some programs of the CDC, including childhood immunizations and lead poisoning prevention. If the Prevention Fund is cut, then these programs will have to compete for a set amount of money with other programs in the health and education appropriations bills. The offset (a.k.a. "pay-for") may be changed as the bill moves through the legislative process.

## **FY 2018 BUDGET RESOLUTION**

In theory, but often not in practice, Congress passes a budget resolution in the spring of each year. Like a bill, a budget resolution must be identical in both chambers of Congress in order to become effective. Unlike a bill, however, a budget resolution is not signed by the president and does not have the force of law. In essence, it is a spending blueprint for Congress to develop its "discretionary spending"

(appropriations) bills, and to amend “mandatory spending” programs (e.g., Medicare, Medicaid, Social Security) and/or tax laws to increase or decrease the deficit or alter tax revenues. The reports accompanying budget resolutions, *assume* certain policy changes - such as cuts in Medicaid or repeal of the ACA - but it is ultimately up to the authorizing committees designated in the “instructions” accompanying the resolution to write the legislation needed to “reconcile” the law with the resolution’s budget goals. The committees’ legislation to accomplish these goals are put together by the budget committee into a single “reconciliation bill,” which is subject to special rules and enjoys special privileges in the Senate. The most significant of these is that a reconciliation bill can be advanced by 51 votes rather than the 60 votes normally needed in the Senate to bring a bill to a vote (to overcome a filibuster or threat of one).

On October 5, the full House approved its FY 2018 budget resolution ([H.Con.Res.71](#)). It calls for tax cuts and trillions of dollars in spending cuts over a decade, including to programs such as Medicaid and Medicare. It provides instructions to 11 committees to achieve \$203 billion in spending cuts; it proposes to cut nondefense discretionary spending by \$5 billion and increase defense spending by \$72 billion. The House Budget Committee [website provides details](#) about the resolution. See also [House passes 2018 budget, taking a crucial step toward tax overhaul](#) (Washington Post *Power Post*, 10/5/17).

Also on October 5, the Senate [Budget Committee](#) approved its [FY 2018 budget resolution](#) along a party line vote. The Senate budget resolution [assumes](#) trillions of dollars in cuts to mandatory programs and proposes a cut of nearly 30% in inflation-adjusted dollars to non-defense discretionary programs by 2027.

In order to allow for a tax cut, the resolution’s accompanying instructions allow the Finance Committee to *increase* the deficit by up to \$1.5 trillion over the next decade. In addition to taxes, the Finance Committee’s jurisdiction includes taxes, Medicare, Medicaid, welfare, Social Security programs (including SSI), and much of the ACA. Because the instructions accompanying the Senate budget resolution specify that the Finance Committee should alter the *deficit*, rather than revenues, the committee could choose to make tax cuts *greater* than \$1.5 trillion and cut spending in programs under its jurisdiction to offset the excess costs of the tax cuts.

The full Senate is expected to take up its budget resolution during the week of October 16. If the resolution passes, as expected, there will be a House-Senate conference committee to work out the substantial differences between the chambers’ respective resolutions.

## **OTHER LEGISLATION**

### **Early Hearing Detection and Intervention Act**

*[From AUCD’s Disability Policy News In Brief, Oct. 9, 2017]*

The Early Hearing Detection and Intervention Act of 2017 (EHDI), has passed in both the [Senate](#) and the [House](#), and is now on its way to the President to be signed into law. The bill reauthorizes newborn hearing screening programs for five years. Before EHDI went into effect in 2000, only 40% of children were being screened for hearing loss at birth. Today, more than 97% of children are screened for hearing loss. The latest bill also made improvements to the program, which now includes "young children" up to age three, and improved access to follow-up testing and intervention services when a hearing loss is diagnosed.

## **RAISE Family Caregivers Act**

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act ([S. 1028](#)), introduced by Senators Susan Collins (R-ME) and Tammy Baldwin (D-WI), has passed the Senate and is heading to the House of Representatives. The Senate-passed bill was amended so that it is consistent with the companion bill recently introduced in the House. The bill would establish an advisory body to bring together representatives from both the private and public sectors to advise and make recommendations regarding a strategy to support family caregivers. The Secretary of Health and Human Services would be required to develop a strategy, to be updated biennially, that would identify actions that communities, providers, government, and others can take to recognize and support family caregivers and would.

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

### **NASHP [Issue Brief](#), [Map](#), [Table](#) and [Blog Post](#) on Medicaid Managed Care for CYSHCN**

The National Academy for State Health Policy (NASHP) has issued several resources about how states are providing services to children and youth with special health care needs (CYSHCN) through Medicaid managed care (MMC) delivery systems, such as risk-based managed care, primary care case management, and prepaid health plans. A [map](#) and [table](#) illustrate key characteristics of states' MMC program design for CYSHCN, including enrollment, whether states define CYSHCN in their managed care contracts, use of behavioral health services in MMC, and requirements for monitoring the quality of care provided to CYSHCN. Additional findings are summarized in the accompanying issue brief, [State Medicaid Managed Care Enrollment and Design for Children and Youth with Special Health Care Needs](#). [View the full 50-state table](#). For an overview of the findings, read the companion blog, [Success Spurs Growth of Medicaid Managed Care for Children and Youth with Special Health Care Needs](#). [View a full list of Children and Youth with Special Health Care Needs Resources](#) from NASHP.

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

### **How Paid Family and Medical Leave Can Promote Employment and Economic Security**

The Arc and the Georgetown Center on Poverty and Inequality have released a new report on how paid family and medical leave can promote employment and economic security for people with disabilities and their families. The report highlights huge gaps in the current United States paid leave system and outlines why a comprehensive and disability-inclusive approach is needed. The Arc has also released a new video and stories profiling several disability perspectives on paid leave. You can access these resources at <http://www.thearc.org/paidleave> or at the links below:

- **Full Report:** [PDF](#) | [Word](#)
- **Stories:** Paid Leave & Disability [PDF](#) | [Word](#)
- **Video:** [YouTube](#)

### **WORTH REPEATING: Family Engagement**

The [National Center for Medical Home](#) Implementation has released a new fact sheet highlighting lessons learned from a family engagement quality improvement project. This fact sheet can be useful for clinicians, Title V staff, family organizations, and others interested in learning about family engagement and quality improvement methodology. Below is some promotional language for your reference:

Developed by the National Center for Medical Home Implementation, this [fact sheet presents lessons learned from a nationwide family engagement quality improvement project](#). The fact sheet provides strategies for implementing family engagement quality improvement projects in clinical practice or through multi-site learning collaboratives, tips for engaging parent/caregiver partners in practice-based quality improvement, and strategies to meaningfully engage families in clinical practice.

## YOUR INPUT SOUGHT

**Deadline, October 31.** To study the impact of rare disease on unpaid friends and family members who provide care (known as “family caregivers”), the National Alliance for Caregiving and [Global Genes](#), are launching a “first-of-its-kind” national snapshot of rare disease caregivers. This fall, the two groups plan to release a national survey aimed at collecting feedback from over 1,000 family caregivers of children and adults with rare diseases. The survey will be open from Wednesday, September 13 through **Tuesday, October 31** with a final report anticipated in early 2018. [Get more information and take the survey.](#)

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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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