



# FAMILY VOICES<sup>®</sup>

Washington DC Update  
April 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!**

Responding to presidential pressure, House leaders tried and failed last week to produce viable legislation to repeal and replace the Affordable Care Act. Although work is continuing on this objective, it remains to be seen whether health care legislation will be revived. The Senate confirmed Judge Neil Gorsuch to be an Associate Justice on the Supreme Court and, in the process, changed very long-standing Senate rules. When they return from their two-week Spring recess the week after next, Members of Congress must fund the government for the remainder of the fiscal year, and then begin work on appropriations for the *following* fiscal year. Read about these topics and more in this week's Update.

**Please note:** Absent unexpected news, there will be no Washington Update for the next two weeks, since Congress is in recess. Important or time-sensitive information, including webinar announcements, will be sent in individual emails. The next Update will be sent on May 3.

**NOTICE:** **Epi-Pen Recall in U.S.** On March 31, the Food and Drug Administration (FDA) [announced](#) the voluntary recall in the U.S. of [13 lots of Mylan's EpiPen and EpiPen Jr](#) (epinephrine injection) Auto-Injector products used for emergency treatment of severe allergic reactions. This recall is due to the potential that these devices may contain a defective part that may result in the devices' failure to activate. See also [Recall of Some EpiPens Extends to U.S.](#) (NPR, 4/3/17)

## **UPCOMING WEBINARS AND CALLS**

### **#Bridge2Health Twitter Town Hall**

**Wednesday, April 12, 1:00 PM ET**

Sponsored by the Department of Health and Human Services (HHS) Office of Minority Health (OMH) This event will highlight examples from around the country of community-based efforts to address health disparities. Organizations can also support efforts to help reduce health disparities by participating in the HHS OMH Health Equity Thunderclap on April 28.

**[Follow-up Discussion: Families Engaging in Title V](#)**

**Wednesday, April 12, 2:00-3:00pm ET**

This is a follow-up to the 3/27 webinar on *Families Engaging with Title V* for participant discussion on the topic. All are invited whether or not you attended the 3/27 webinar. Focus will be on group discussion: What are the most valuable ways you find to engage families in the block grant process in your state? What are the challenges? What do you need? Materials and recording from the 3/27 presentation can be accessed [here](#), and you can find resources on engaging with Title V [here](#).

**[Pediatric Hearing Loss: Offering Parent Support Groups for Hispanic Families](#)**

**Wednesday, April 12, 2:00-3:00 pm ET**

Sponsored by the National Center for Hearing Assessment and Management, Utah State University

**[Marketplace Webinar: From Coverage to Care](#)**

**Wednesday, April 12, 2:00-3:30 pm ET**

Sponsored by the Centers for Medicare and Medicaid Services (CMS); intended for Navigators, enrollment assistance personnel, and certified application counselors (CACs)

This webinar address the CMS Office of Minority Health's publication [From Coverage to Care: A Roadmap to Better Care and a Healthier You](#), highlighting information on helping consumers understand their health coverage. There will also be a review of the posted CMS guidance, [Tips for Assisters on Working with Outside Organizations](#).

**[The Kind of Leadership We Need: Embracing Our Diversity as Leaders in Systems Transformation](#)**

**Wednesday, April 12, 3:30-5:00 pm ET**

Sponsored by the Substance Abuse and Mental Health Services Administration

**[Using Community Health Workers and Volunteers to Reach Complex Needs Populations](#)**

**Tuesday, April 18, 1:00-2:30 pm ET**

Sponsored by the [Center for Health Care Strategies](#) (funded by Kaiser Permanente Community Benefit and the Robert Wood Johnson Foundation)

**[Looking at Institutional and Community Living Through Data- An ADA Participatory Action Research Consortium \(ADA-PARC\) Report](#)**

**Wednesday, April 19, 2:00 pm ET**

Sponsored by the Great Lakes ADA Center

**[Back to the Basics: Medicaid's EPSDT Benefits](#)**

**Thursday, April 20, 1:00 pm ET**

Sponsored by the Georgetown Center for Children and Families

**[Cultural Sensitivity When Collecting Sensitive Data](#)**

**Thursday, April 20, 1:00 - 2:00 pm ET**

Sponsored by the National Partnership for Action to End Health Disparities; part of the Mountain States Regional Health Equity Council's Native American Cultural Competency Series (Populations featured: American Indians, African-Americans, and rural communities in SC)

### [What to Do \(And Not Do\) When Children Are Anxious](#)

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

Sponsored by the National Institute of Mental Health

### [Engaging Diverse Families in Leadership for Systems Change](#)

Thursday, April 20, 3:00-4:30 pm ET

Sponsored by the National Center for Family Professional Partnerships

### [Drug Pricing: Where's the Future Headed?](#)

Wednesday, April 26, 1:00-2:00 pm ET

Sponsored by Avalere Health

### [Understanding Depression in Teenagers](#)

Thursday, April 27, 1:00-2:00 pm ET

Sponsored by the National Institute of Mental Health

### [Working with Adult Allies](#) (for young adults only)

Tuesday, May 16, 7:30-8:30 pm ET

This is the last of a three-part webinar series sponsored by the National Center for Family Professional Partnerships (NCFPP), in collaboration with the Autistic Self-Advocacy Network, Kids As Self-Advocates, and Youth MOVE. **Completed webinars: *Participating in Advisory Groups; Telling Your Story for a Public Policy Purpose.***

## **APRIL IS MINORITY HEALTH MONTH**

The U.S. Department of Health and Human Services (HHS) Office of Minority Health (OMH) has launched the annual observance of [National Minority Health Month](#). The theme this year, *Bridging Health Equity across Communities*, emphasizes the collaborative, community-level work being done across the nation to help achieve health equity. As part of the 2017 observance, HHS OMH will host a [#Bridge2Health Twitter Town Hall](#) at **1:00 PM EDT on April 12** that will highlight examples from around the country of community-based efforts to address health disparities. Organizations can also support efforts to help reduce health disparities by participating in the HHS OMH Health Equity Thunderclap on April 28.

## **CONGRESS**

### **Supreme Court Nominee**

On April 7, the Senate [confirmed Judge Neil Gorsuch](#) as Associate Justice of the U.S. Supreme Court by a vote of [54-45](#), mostly along party lines. Three Democrats voted for the confirmation – Senators Joe Manchin (D-WV), Heidi Heitkamp (D-ND) and Joe Donnelly (D-IN) – all of whom are up for reelection in 2018. In objection to the nomination, Democrats decided to filibuster the motion to proceed to a vote. To stop the filibuster, 60 votes were needed to invoke “cloture” (an end to debate). The vote on cloture fell short of this number, however, so Senate Majority Leader Mitch McConnell (R-KY) invoked the so-called “[nuclear option](#).” This refers to using a simple majority vote (51) to reinterpret the Senate

rules so that cloture could be invoked on Supreme Court nominations with a simple majority vote. As a result, all future Supreme Court nominees can be confirmed with a simple majority vote, even if a filibuster is conducted. When the Democrats controlled the Senate, then-Majority Leader Harry Reid (D-NV), employed the nuclear option to clear nominees to lower federal courts.

### **ACA Replacement Legislation**

After the March 24 cancellation of a vote on the American Health Care Act (AHCA) — the House Republican bill to repeal and replace the Affordable Care Act (ACA) — it seemed that efforts to repeal and replace the ACA were on the back burner for the foreseeable future. But, last week, the legislation seemed to rise from the dead. At the beginning of last week, Vice President Mike Pence visited Capitol Hill to see if an agreement could be worked out with the House Freedom Caucus, the group of conservative Republicans who had objected to the AHCA. The administration proposed allowing the Secretary of Health and Human Services (HHS) to let states waive certain ACA provisions, particularly the requirement that insurance plans cover ten "Essential Health Benefits," and the "community rating" requirement, which prevents insurers from charging higher rates to individuals with pre-existing conditions. But the Caucus leaders were not ready to make any commitments until they could see legislative language.

On Wednesday, the president met with House Speaker Paul Ryan (R-WI) and Majority Leader Kevin McCarthy (R-CA), [reportedly pressuring them](#) to see if they could get a bill through the House before adjourning before a two-week recess, scheduled to begin on Friday. As a result, there was a last-minute rush to develop some legislation that might be approved. An [amendment to the AHCA was proposed](#) to create a "[Federal Invisible Risk Sharing Program](#)," through which funds would be provided to insurers to compensate them for very high-cost individuals, with the goal of reducing premiums in general. See [House GOP Moves To Add 'Invisible Risk Sharing Program' To AHCA; Other ACA Developments](#) (Health Affairs Blog, 4/6/17); [To Revive Health Bill, GOP Adds an Obamacare-Like Subsidy](#) (Bloomberg, 4/6/17). Nonetheless, there was not a sufficient consensus to get a bill through the House.

Given the president's desire to get something done on health care, some House Members and staff will be working during the current recess to see if they can negotiate a bill that can pass the House. There has even been talk of the House cutting short its recess to come back for a vote if a viable bill is negotiated. At this point, that does not seem likely, however. In an [interview](#) reported on April 5, Speaker Ryan said he thought the process of developing alternative legislation would take weeks, not days, and that there is no artificial deadline. Finding a plan that will please both ends of the Republican spectrum will not be easy. Many House Members of both parties want to retain the ACA's protections for people with pre-existing conditions, while Freedom Caucus Members would like to eliminate this and other regulations, such as the ACA-required Essential Health Benefits.

### **Medicaid**

In addition to repealing and replacing the Affordable Care Act (ACA), the American Health Care Act (AHCA) (see above) would have made fundamental changes to the Medicaid program — capping federal Medicaid payments to states through per capita caps, with an option for states to choose block grants and fewer federal regulations instead. (See Washington Update of [March 29](#).) In addition, the AHCA would have made significant cuts to the program -- \$880 billion over ten years, which would amount to a cut of about 25 percent by 2026, compared to current law. The nonpartisan Congressional Budget

Office (CBO) estimated that, by 2026, about 14 million fewer people would be eligible for Medicaid if the AHCA were enacted than if current law remained in place. These Medicaid changes could be made whether or not the rest of the ACA is repealed or modified. Given the significant amount of federal savings that these changes would yield, it may be tempting for Congress and/or the administration to propose the Medicaid changes to pay for the tax cuts that are high on their agendas. Reportedly, some members of the Senate are discussing this possibility. See [If Trumpcare stays dead, Medicaid overhaul could come back to life](#). At *Arizona Symposium on Children with Special Health Care Needs* recently held in Phoenix, the head of the Arizona chapter of the American Academy of Pediatrics spoke about the harms that Medicaid cuts could have on children and youth with special health care needs. See [Doctors say repeal of Obamacare would stop Medicaid coverage for children with disabilities](#) (Cronkite News, April 10, 2017)

### **Budget/Appropriations**

A major task ahead of Congress when it returns from its spring recess on April 24<sup>th</sup> (Senate) and Tuesday the 25<sup>th</sup> (House) is to fund the government for the remainder of FY 2017, which ends on September 30. Current funding expires on Friday, April 28, pursuant to a “continuing resolution” (CR), which has basically kept appropriations at FY 2016 levels. It will especially difficult to reach a deal if some Members push for significant policy changes or initiatives, such as the defunding of Planned Parenthood or the construction of a wall between the U.S. and Mexico. If no deal is reached by April 28, another short-term CR could be enacted while negotiations continue, there could be a temporary government shutdown, or a CR could be enacted to last through the end of the fiscal year. If the House, Senate, and White House can all agree to changes from FY 2016 spending levels, then there will probably be an “omnibus” appropriations bill, one large bill combining the appropriations bill for many federal departments and agencies. Meanwhile, the appropriations process for FY 2018 has begun. In March, the president submitted to Congress his proposed FY 2018 budget, which was dubbed a “skinny budget” because it provided little details and covered only appropriated spending (not taxes or mandatory spending). He will submit a more complete budget proposal in May. Congress will then hold hearings and develop its own spending bills.

### **ABLE Act Bills**

*[from AUCD’s Disability Policy News in Brief, 4/10/7]*

On April 4th, a bi-partisan group of Members of Congress, including Senators Burr (R-NC), Casey (D-PA), Moran (R-KA), and Van Hollen (D-MD), and Representatives Pete Sessions (R-TX), Cathy McMorris Rodgers (R-WA), Tony Cardenas (D-CA) and Mike Doyle (D-PA) re-introduced the package of bills aimed at enhancing the benefits provided through the [Stephen Beck Jr., Achieving a Better Life Experience \(ABLE\) Act](#). This package of bills consists of the following three pieces of proposed legislation: The [ABLE Age Adjustment Act \(S. 817/HR 1874\)](#) would raise the age limit for ABLE accounts to age 46 (currently 26); [ABLE Financial Planning Act \(S. 816/HR 1897\)](#) would allow families to rollover savings in a 529 college savings plan into an ABLE account (and would still be subject to the annual contribution limit of \$14,000); [ABLE to Work Act \(S. 818/HR 1896\)](#) would allow individuals and their families to save more money in an ABLE account if the beneficiary works and earns income.

For more information, see [Members of Congress Re-Introduce ABLE Improvement Bills](#), from the ABLE National Resource Center.

## CHIP

Also coming up on the congressional agenda is an extension of funding for the Children's Health Insurance Program (CHIP). Although the program is authorized through FY 2019, it is funded only through FY 2017 (which ends on September 30), pursuant to legislation enacted in 2015. Child health advocates have been working to educate Congress – particularly new Members and staffers -- about the importance of the CHIP program to ensuring children's coverage. The program now insures about 9 million children, many of whom would not have access to affordable insurance otherwise. The Medicaid and CHIP Payment and Access Commission (MACPAC), recently released a [new analysis](#) projecting when states will begin to exhaust their federal CHIP funds, which is an update of projections made in the Commission's January 2017 [Recommendations for the Future of CHIP and Children's Coverage](#). MACPAC recommended that CHIP funding be extended for an additional five years.

## ACA NEWS, INFORMATION AND RESOURCES

### Market Stabilization Rule and Network Adequacy

In February, the administration issued a [proposed rule](#) under the Affordable Care Act (ACA) that is intended to help stabilize the individual and small group markets. The proposed rule would amend standards relating to special enrollment periods, guaranteed availability, and the timing of the annual open enrollment period in the individual market for the 2018 plan year. It would also amend standards related to network adequacy and essential community providers for qualified health plans, and the rules around actuarial value requirements. An [April 6 blog post](#) from the Georgetown Center on Health Insurance Reforms (CHIR) discusses how this proposed rule relates to network adequacy of insurance plans. An [earlier CHIR blog post](#) discusses the impact of the proposed shortening of the ACA open enrollment period.

## MEDICAID NEWS, INFORMATION AND RESOURCES

The Medicaid and CHIP Payment and Access Commission (MACPAC) recently released several resources related to Medicaid:

- [How states exercise flexibility in their Medicaid programs](#) including eligibility pathways, benefits, and payment policies. Stay tuned for additional briefs on enrollment processes, cost sharing, and other topics soon.
- [The mechanics of setting per capita caps](#), in particular, the extent to which Medicaid managed care rate setting and the process for establishing budget neutrality limits in Section 1115 demonstration waivers are useful analogues in considering how caps might be set at the national level.
- [Key design elements of per capita caps and block grants](#).
- [A detailed look at Medicaid spending](#) over time, compared to other payers, and drivers of growth.
- How states and Medicaid managed care plans are responding to the [high costs of specialty drugs](#).

Other MACPAC publications related to Medicaid include:

- Access in brief series: [Adults](#) with Medicaid are much more likely to have a usual source of care than uninsured adults and as likely as privately insured patients to have a usual source of care. Nevertheless, patients with Medicaid are more likely to experience other barriers to care than privately insured patients. A separate set of issue briefs contains similar findings for [children](#) with Medicaid coverage.
- Compendia of state Medicaid payment policies that detail [fee-for-service physician payment policies](#), [state Medicaid policies for Medicare cost sharing](#), and [Medicaid payment policies for outpatient hospital services](#) for every state.
- MACPAC's newest policy spreadsheet that inventories [the functional assessment tools](#) used by each state to determine eligibility and develop care plans for long-term services and supports.
- [MACStats](#), MACPAC's repository of difficult-to-find Medicaid and CHIP statistics and information.

## Other Medicaid Resources

[Case Study: How Minnesota Uses Medicaid Levers to Address Maternal Depression and Improve Healthy Child Development](#) (National Academy for State Health Policy)

[Background to Medicaid and Section 1115 of the Social Security Act](#) (National Health Law Program)

[Waivers of Medicaid Requirements - A Quick Review](#) (National Health Law Program)

## ZIKA

On April 5, nearly 50 Members of Congress from both the House and the Senate sent a bipartisan [letter](#) to the President asking that funding be distributed in a timely manner to fight Zika and accelerate research on a vaccine.

## TRICARE

### TRICARE Dental Program

Beginning on May 1, 2017, United Concordia Companies, Inc. (United Concordia) will manage the TRICARE Dental Program (TDP). Beneficiaries do not need to take any actions to continue their coverage. Read the full article [here](#).

## OTHER NEWS, INFORMATION, RESOURCES

### WORTH REPEATING: Field Guide to Managed Care

The American Society on Aging has published [The Field Guide to Managed Care: A Primer](#). As described in the publication's introduction, "This Field Guide parses the landscape of managed care: what it is, why it is necessary, and how community-based organizations (CBO) and healthcare entities are partnering to [affect] it. As well, real-life case studies share lessons CBOs have learned in their journeys to managed care, and offer thoughts on what the future of managed care might hold."

## YOUTH PEER SUPPORT

### **NEW:** [Effectively Employing Young Adult Peer Providers: A Toolkit](#)

The University of Massachusetts Medical School, Department of Psychiatry, Systems and Psychosocial Advances Research Center (SPARC), Transitions Research and Training Center (RTC), have just released a toolkit for effectively employing young adult peer providers. The toolkit was developed specifically for provider organizations that employ or want to employ young adult peer providers.

### **WORTH REPEATING: Medicaid Funding for Youth Peer Support**

[Youth Move National](#) provides a number of [resources](#) about youth peer support, including the [Youth Peer Medicaid Guide](#) (47 pp. PDF), which explains how states can establish coverage for youth peer support through Medicaid State Plan Amendments or waivers.

## OF POSSIBLE INTEREST

[Did caring for a profoundly sick daughter cost a mother her job at Walmart?](#)

[Eating Fish: What Pregnant Women and Parents Should Know](#) (issued by the FDA)  
[In Spanish](#)

## YOUR INPUT SOUGHT

### **Deadline April 30 (extended). The Arc Seeks Caregivers for FINDS Survey**

With the new year comes a new [Family and Individual Needs for Disability Supports \(FINDS\) Survey](#). The Research and Training Center on Community Living at the University of Minnesota, in collaboration with The Arc, is seeking caregivers to share their perceptions on a range of life-span issues impacting individuals with I/DD. The Arc invites people aged 18 years or older who provide frequent primary support to a person with I/DD to participate. [Take the survey here](#).

### **Parent/Guardian Survey Opportunity Regarding Children with Autism Spectrum Disorder and School Based Services**

Researchers at the University of South Dakota are conducting research on behalf of the *South Dakota Leadership Education in Neurodevelopmental and Related Disabilities* (SD LEND) program regarding the services your child receives in their school. They are interested in what autism symptoms your son/daughter exhibits, what kinds of social-emotional services they receive at school, and MOST IMPORTANTLY **your** opinions about what could be improved with these services. The completely anonymous online survey will take 20-25 minutes to complete. Your contributions to this research might help further inform the professionals serving your child, and hopefully benefit the wider ecosystem in which your child will spend her/his life. Please click on the link to participate: [https://usdsoe.qualtrics.com/SE/?SID=SV\\_5cnEfOytThLu65n](https://usdsoe.qualtrics.com/SE/?SID=SV_5cnEfOytThLu65n)

### [Comment Sought on Department of Education IDEA Website](#)

The Office of Special Education and Rehabilitative Services requests public comment as it works to create a new and improved website to provide essential information and resources related to services children are entitled to under the IDEA (Individuals with Disabilities Education Act).

### **Youth Voice Agency-Level Evaluation Study**

Do you work for or with an organization that wants to include youth and young adult voice in agency decision-making? Then you're invited to take part in a study that is testing a new assessment survey of youth and young adult voice at the agency level. The survey will measure organizational support for the meaningful participation of youth in agency-level advising and decision-making. In partnership with researchers at Portland State University, this study will determine whether the survey is accurate for agencies to use. If you're interested in either of these opportunities, contact Kristin Thorp at [kthorp@youthmovenational.org](mailto:kthorp@youthmovenational.org) for more info.

=====

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

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U40MC00149. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.