



FAMILY VOICES[®]

Washington DC Update
February 1, 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 new president has been in office less than two weeks and has been keeping up a fast pace of activity. After his January 20 [Executive Order](#) instructing federal agencies to limit activities related to implementation and enforcement of the Affordable Care Act (ACA), he [halted ads and other outreach efforts](#) to promote of the ACA open-enrollment period (which ended on January 31), but then changed his mind and [re-instituted some of these efforts](#). He also issued an order to limit immigration from certain countries with Muslim majorities, causing consternation among medical schools with foreign students, and health care providers that employ foreign medical and nursing professionals and serve [foreign patients in need of specialty care](#). Meanwhile, more Republicans in Congress seem to be expressing concern about a swift repeal of the ACA without having a replacement lined up, but there is no agreement on how to replace it. At his confirmation hearing, to be the new Secretary of Health and Human Services, Rep. Tom Price, MD (R-GA) made a surprising comment in support of the Children's Health Insurance Program (CHIP). And new state-by-state resources are available about the impact of Medicaid and the ACA. Read about these issues and more in this week's Update.

UPCOMING WEBINARS AND CALLS

[Health for All Adolescents: What is Shaping Adolescent Health Today and How Can You Help](#)

Wednesday, February 1, 11:00 am-12:30 pm ET

Sponsored by the American Public Health Association

[Treatment Across the Lifespan for Persons with Fetal Alcohol Spectrum Disorders](#)

Wednesday, February 1, 4:00-4:30 pm ET

Sponsored by the American Academy of Pediatrics

[Family-to-Family Health Information Centers & EHDl Programs: Engaging & Supporting Families of Children with Deafness & Hearing Loss](#)

Wednesday, February 8, 2:00 pm ET

Sponsored by the National Center for Hearing Assessment and Management and Family Voices

[Integrated Health: the Basics](#)

Thursday, February 9, 3:00-4:00 pm ET

Sponsored by Catholic Charities USA

[Engaging Medicaid Patients: Obstacles, Successes & the Impact of Medicaid Waivers*](#)

Friday, February 10, 1:00-2:30 pm ET

Sponsored by the National Institute for Health Care Management (NIHCM) Foundation
[Note that Family Voices Board member Merrill Friedman, of Anthem, Inc., will be one of the presenters during this webinar.]

**This link looks like it is for a different webinar, [Transforming Health Care through Evidence and Collaboration](#), but, despite being labeled with a future date, that webinar already took place.*

[Relationship-Centered Care: A Healthcare Provider's Guide to Patient Engagement, Shared Decision Making, and Improved Outcomes](#)

Thursday, February 16, 1:00-2:00 pm ET

Sponsored by Health Management Associates (registration required)

[Overview of Working with Tribal Governments](#)

February 16, 1:00-2:00 pm ET

Sponsored by the Mountain States Regional Health Equity Council and the Office of Minority Health Resource Center

[2017 Learning and Reflection Forums](#) of the Leadership Institute for Cultural Diversity and Cultural and Linguistic Competence at the National Center for Cultural Competence:

[Leading in Communities with Deep Historical Wounds](#)

Thursday, February 16, 2:00-3:30 pm ET

[Getting Buy In and Implementing Cultural and Linguistic Competence Organizational Assessment](#)

Thursday, March 16, 2:00-3:30 pm ET

[Developing Organizational Policies that Reflect the Values of Cultural & Linguistic Competence](#)

Thursday, April 6, 2:00-3:30 pm ET

THE ADMINISTRATION

Supreme Court Nomination

On January 31, President Trump [nominated Neil Gorsuch](#) to the Supreme Court.

ACA Executive Order

As reported in last week's Update, President Trump issued an [Executive Order](#) directing the Secretary of Health and Human Services and other applicable agency and department heads to use their discretion to limit implementation and enforcement of the Affordable Care Act (ACA or "Obamacare") if it would cause a fiscal burden for any individual or entity, and to provide greater flexibility to states in implementing their health care programs. At this point, it is still unclear how great the impact of this directive will be. The National Health Law Program (NHLP) has developed a [Q & A information brief](#) on this particular Executive Order (explaining its limits) and a one-page [fact sheet on the nature of presidential Executive Orders in general](#).

ACA Enrollment Outreach

Just days before the end of the ACA open-enrollment period, the administration decided to [halt advertising, “tweeting,” and other efforts](#) to encourage consumers to purchase health insurance. Many advocates were concerned about this decision, some suggesting that it was an intentional move to undermine the law, because many younger, healthier people tend to enroll at the last minute and they are needed to ensure a balanced insurance pool. In a move that some experts thought could have a material impact, the administration stopped sending emails to encourage enrollment by individuals who visited HealthCare.gov but had not completed the enrollment process. The next day, however, the [administration reversed its decision in part](#). It started to send out emails and tweets again, and said it would not pull ads that had been paid for already but would not purchase new ads.

CONGRESS

ACA Repeal

In general. As reported in earlier Updates, the House and Senate have adopted a [concurrent budget resolution](#) -- the first step in the ACA repeal process. At this point it is entirely unclear when there will be any repeal and/or replacement legislation. A recording of a closed-door meeting at the Republican congressional retreat last week [reveals disagreement](#) within the party about how and when to proceed with repeal and replacement of the ACA. Some Members are anxious to get the repeal done, since that’s what the president and many Members of Congress promised during their campaigns. Others caution that they should proceed without haste, fearing that repeal without replacement will cause a collapse of the individual insurance market, which would be blamed on the Republicans. While most Members of Congress would probably be happy to replace the ACA at the same time they repeal it, there is [no consensus on how to do so](#).

Medicaid expansion. A particularly thorny issue involved in ACA repeal is what to do about the law’s Medicaid expansion. Before the ACA, childless adults were not eligible for Medicaid. The ACA as written would have required every state to provide Medicaid coverage to *all* individuals with incomes below 100 percent of the federal poverty level, providing significantly enhanced federal matching payments to states for the cost of covering those who were previously ineligible (the “expansion population”). The Supreme Court effectively made this Medicaid expansion optional for states. As of January 2017, [32 states \(including the District of Columbia\)](#) have taken up the expansion option. Thus, if the Medicaid expansion provision of the ACA is repealed, these states will lose millions of federal dollars, with significant ramifications for the state’s health care providers, cities and counties, and/or taxpayers. This creates a dilemma for Members of Congress wishing to repeal the ACA and cut federal spending without hurting their own states that have expanded Medicaid. At least **8 Republican Governors** are warning Congress about the consequences of repeal, including: Utah **Gov Herbert**, Massachusetts **Gov. Baker**, Arizona **Gov. Ducey**, Michigan **Gov. Snyder**, Ohio **Gov. Kasich**, Arkansas **Gov. Hutchinson**, Nevada **Gov. Sandoval**, and Kentucky **Gov. Bevin**. (See [positions of specific Republican governors](#).)

A January 24, letter from the National Governors Association to congressional leaders reflects this problem. The letter requests that Congress consider several factors as they undertake health care reform, including the need to involve governors in the development of legislation. The governors seek flexibility, but say “it is critical that Congress continue to maintain a meaningful federal role in this

partnership and does not shift costs to states,” and that reforms “should protect states from unforeseen financial risks – such as the recent economic downturn or higher costs due to new drugs, treatment, or epidemics – that could result in a spike in Medicaid enrollment or increased per-beneficiary costs.”

Public response. As noted in last week’s Update, Members of Congress have [heard from many constituents](#) who oppose ACA repeal in the absence of a simultaneous replacement. As of last week, at least **10 Republican Senators** were on the record expressing concern about repeal without replacement, including: [Sen. Alexander](#), [Sen. Collins](#), [Sen. Corker](#), [Sen. Cotton](#), [Sen. Flake](#), [Sen. Isakson](#), [Sen. Johnson](#), [Sen. McCain](#), [Sen. Murkowski](#), [Sen. Paul](#), and [Sen. Sullivan](#).

State-specific Information:

- To see how the ACA has impacted your state, see [ACA state fact sheets developed by HHS](#).
- To see how ACA repeal might affect your state, see [state fact sheets on ACA repeal from Families USA](#).
- For state-specific data on Medicaid coverage, access and financing, see [state Medicaid fact sheets](#) from the Kaiser Family Foundation.
- The National Academy for State Health Policy (NASHP) has developed a [chart](#) which provides an overview of ACA provisions and a snapshot of the implications for state health insurance laws and regulations and a number of other consequences if the ACA is repealed.

Replacement legislation. As noted above, there is no consensus about how to replace the ACA while retaining its popular consumer protections. Several Members of Congress have proposed ACA alternatives, but the administration has not yet done so. It is possible that it will, once Rep. Price is confirmed as HHS Secretary, assuming that happens. (There was an abrupt [cancellation of a vote](#) on his nomination scheduled in the Finance Committee on Tuesday.) Such a proposal could be based on a [plan put forward by HHS Secretary-nominee Rep. Price in 2014](#) or a similar plan put forward by House Speaker Paul Ryan (R-WI) in his [“Better Way” health care proposal](#). Among other things, both plans would provide tax credits to purchase insurance, encourage the creation of Health Savings Accounts (from which pre-tax dollars could be used to purchase health care), and allow the sale of health insurance plans across state lines. Senate Democratic Leader Chuck Schumer (D-NY) [indicated that Senate Democrats would be willing to work with Republicans](#) to develop an ACA replacement plan, but would do so only *before* repeal of the ACA.

Recently, several Senators have developed replacement bills:

Cassidy-Collins bill. On January 23, Senators Bill Cassidy, MD (R-LA), Susan Collins (R-ME), Shelley Moore Capito (R-WV) and Johnny Isakson (R-GA) released [legislative text](#) for the Patient Freedom Act of 2017, a comprehensive replacement plan for Obamacare. Among other things, the bill would repeal the ACA’s individual and mandates to have insurance, and its “essential health benefit” requirements while retaining some consumer protections, including the prohibitions on annual and lifetime limits, and coverage of treatment for mental health and substance use disorders. The bill would also create high-risk pools for people with pre-existing conditions. (For [more details](#), see Senator Collins’ website.) During the past week, there have been several summaries and analyses of the Cassidy-Collins bill, including a [thorough summary](#) by Tim Jost, a blogger for Health Affairs, and an analysis from the [Center for Budget and Policy Priorities](#). The National Health Law Program has prepared a three-page critique,

[Nine Things to Know About the Cassidy-Collins 'Replacement](#). Joan Alker, Executive Director of the Georgetown Center for Children and Families, [blogged](#) about the Cassidy-Collins proposal and the idea of ACA replacement in general.

Rand Paul bill. Senator Rand Paul (R-KY) has also developed and introduced ACA replacement legislation (S. 222), as described in this [press release](#) and this [CNN story](#).

Medicaid Restructuring

News. On January 19, Senate [Finance Committee](#) Ranking Member Ron Wyden (D-OR), along with every Democratic member of the Committee, today [sent a letter](#) to all governors (Democrats and Republicans) asking for feedback on the expected impact of Republican proposals to block grant or cap Medicaid. Responses are requested by February 15. In December, Finance Chairman Hatch (R-UT) and the other Republican committee members sent a [letter to all Republican governors and insurance commissioners](#) asking for their input on Medicaid reforms and inviting the governors to a January Roundtable discussion about the issue. The [Roundtable](#) took place on January 19, with ten Republican governors participating.

On January 26, the Medicaid and CHIP Payment and Access Commission (MACPAC) held a meeting at which they [discussed possible options for Medicaid restructuring](#), and released related reports. (See Information section, below.)

Background. For some years, some conservatives have proposed restructuring the Medicaid program into a block grant to states – meaning each state would get a fixed amount based on its historical costs but not related to current state Medicaid enrollment numbers – or paying states a limited amount per person covered (per capita cap). The Trump administration has also said it favors this type of Medicaid restructuring. Block grant proposals entail giving states much greater flexibility in determining Medicaid eligibility and benefits. Block grant proponents argue that this would allow states to innovate in ways that would serve beneficiaries more efficiently. But the congressional proposals to restructure the federal financing of Medicaid all involve cutting federal contributions to states compared to what they would get under the current entitlement structure of the program. Thus, states, localities and health care providers will have to bear relatively more and more costs as time goes on. See [Republican ideas for healthcare reforms could spell trouble for U.S. states](#) (Reuters article).

Information. For more information about block grants and per capita caps, see:

- [Everything You Need to Know about Block Grants](#), from Kaiser Health News
- [Caps on Federal Medicaid Funding Would Give States Flexibility to Cut, Stymie Innovation](#), from the Center for Budget and Policy Priorities.
- [Alternative Approaches to Medicaid Financing: Background and Context](#), from MACPAC
- [Alternative Approaches to Medicaid Financing: Choice of Design Elements in Alternative Financing Proposals](#), from MACPAC

Nominations

The Senate is responsible for confirming Cabinet nominees, and its various committees are now holding confirmation hearings. If a relevant committee recommends confirmation, then the full Senate will vote on the nomination.

Secretary of HHS. [Rep. Tom Price](#), MD (R-GA), a former orthopedic surgeon and long-time opponent of the Affordable Care Act, has been nominated to be the Secretary of Health and Human Services. Surprisingly, during his official [confirmation hearing](#) before the Senate Finance Committee on January 24, Rep. Price expressed his belief that funding for the Children’s Health Insurance Program (CHIP) should be extended – *for eight years*. As [reported by The Hill](#), when asked by Ohio Sen. Sherrod Brown (D-OH) if he thought the funding should be extended for another five years (which was [recommended by the Medicaid and CHIP Payment and Access Commission](#)), Rep. Price replied: “Well, if we could extend it for eight, that’d probably be better than five.” (You can watch this exchange at the 1:55 point on the [recording](#) of the committee meeting.) The committee was scheduled to vote Tuesday on whether to recommend his confirmation to the Senate, but the [vote was abruptly postponed](#) when the Democrats decided to boycott the meeting due to questions about Price’s stock transactions.

Secretary of Education. As reported last week, the Senate Health, Labor, Education and Pensions (HELP) Committee held a very long confirmation hearing for the nominee to be the Secretary of Education, [Betsy DeVos](#), at which she seemed not to be very familiar with the Individuals with Disabilities Education Act (IDEA). ([Watch the archived hearing](#); the IDEA discussion begins at the 3 hour and 31 minute mark.) Ms. DeVos subsequently wrote a [letter to Sen. Isakson](#) to clarify her views on that law. As explained in a [Washington Post article](#), special education advocates were not reassured by her letter, however. After the hearing, some of the members of the Consortium of Citizens with Disabilities (CCD), including Family Voices, sent a letter to Chairman Alexander and Ranking Member Patty Murray (D-WA) to request that a vote on the nomination be postponed until Ms. DeVos answers additional questions (specified in the letter) regarding her views on policies affecting students with disabilities. The vote was not postponed in response, however. On January 31, the [committee recommended](#), on a party-line vote, that Ms. DeVos be confirmed. Full Senate consideration of her nomination has not yet been scheduled. Given strong grassroots opposition to the nomination, reflected by calls to Senate offices, ultimate confirmation is not guaranteed. Although it would take three Republican Senators to break party rank, at least one - Sen. Lisa Murkowski (R-AK) - has [expressed reservations](#).

Attorney General. [Senator Jeff Sessions](#) (R-AL), has been nominated to be the U.S. Attorney General. His nomination has been controversial and is opposed by many advocates. Based on the Senator’s record of opposing protections for people with disabilities as the Alabama Attorney General and as a Senator, several disability groups [sent a letter](#) to the Judiciary committee opposing the nomination. The Judiciary Committee was scheduled to vote on the nomination on January 31, but Democrats’ objections delayed the vote until February 1.

MEDICAID NEWS, INFORMATION AND RESOURCES

Information on Medicaid restricting proposals: See links above

How Medicaid Helped One Little Girl

This week the Georgetown Center for Children and Families blog offers a compelling [story](#) of a little girl with Rett Syndrome and how the Medicaid program has helped her.

ZIKA

[Florida](#) has identified 4 new cases of Zika in 2017 – all travel-related, while [Texas](#) has reported the first case of [local transmission](#) to a pregnant woman.

The March of Dimes has organized a [Zika Coalition](#), for which a website has just launched. If your organization would like to be listed, please fill out this [google document](#).

WORTH REPEATING: Training Materials from the Centers for Disease Control and Prevention (CDC):

- [Grand Rounds Presentation: Zika & Infants](#) and [Grand Rounds Presentation: Zika & Pregnancy](#)
- [Tips for communicating with your baby's doctor or healthcare provider](#) [198 KB, 1 page]

CULTURAL COMPETENCE

WORTH REPEATING: New Minority Health Toolkit Released

CMS and the National Committee on Quality Assurance have released a [toolkit](#) aimed at improving health care for minorities and at-risk populations, including people with limited English proficiency, sexual minorities and people with disabilities.

OTHER NEWS, INFORMATION, RESOURCES

[Joint Statement on Collaboration and Coordination of the MIECHV and IDEA Part C Programs](#)

The U.S. Departments of Education ([ED](#)) and Health and Human Services ([HHS](#)) released a [Joint Policy Statement on Collaboration and Coordination of the Maternal, Infant, and Early Childhood Home Visiting and the Individuals with Disabilities Education Act Part C Programs](#).

YOUR INPUT SOUGHT

The Arc Seeking 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](#).

OF POSSIBLE INTEREST

[Let's Be Sure Children Aren't Lost in the Healthcare Debate](#) – Op-ed in *The Hill* by Madeline Bell, president and chief executive officer of the Children's Hospital of Philadelphia, and chair of the Board of Trustees for the Children's Hospital Association.

WORTH REPEATING: Disability Policy Seminar - Registration for the 2017 Seminar is open

The 2017 Disability Policy Seminar will be held on March 20-22 in Washington, D.C. This event, sponsored by The Arc and several other disability-related organizations, provides an opportunity to cultivate congressional relationships and advance the grassroots movement for people with intellectual and developmental disabilities (I/DD). For over 40 years, the Policy Seminar has offered the opportunity for participants to join other advocates, self-advocates, experts, and professionals in the field to learn about key issues. [Register here](#).

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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,
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.