



FAMILY VOICES[®]

Washington DC Update
January 10, 2018

The Family-to-Family Health Information Centers (F2Fs) and the Family Voices State Affiliate Organizations (FV SAOs) have been busy helping families with children and youth with special health care needs navigate the complex world of health care. Please check out the [2017 Activity Highlights](#) from these family-led organizations around the country.



Greetings from Washington! Happy New Year! Congress is back in session, trying to figure out how to fund the government past January 19. In the mix are a number of issues, including funding for the Children’s Health Insurance Program (CHIP), community health centers, and other programs (e.g., Family-to-Family Health Information Centers); disaster funding; whether to address the situation of undocumented immigrants brought to this country as children (“Dreamers”); whether to build a wall on the U.S.-Mexico border; relative spending levels for defense and non-defense programs; and legislation to provide cost-sharing reduction payments to insurers and to fund state reinsurance programs.

From the Executive Branch: The **Department of Labor issued a proposed rule** regarding the creation of “association health plans,” which could make less robust, less expensive insurance policies available to some people, but cause premiums to increase for people who want or need more generous benefits. The **Social Security Administration issued a Request for Information** about how to improve adult outcomes for youth receiving Supplemental Security Income (SSI). The **Substance Abuse and Mental Health Services Administration (SAMHSA) issued a final rule** amending its regulations governing the Confidentiality of Substance Use Disorder Patient Records. The **Department of Justice withdrew its guidance** on ADA compliance by state and local governments’ employment service systems.

The congressionally-created **Medicaid and CHIP Payment and Access Commission (MACPAC) released its most recent data on Medicaid and CHIP:** [press release and highlights](#); [data](#).

UPCOMING WEBINARS AND CALLS (ALL TOPICS)

[Stress and Gastrointestinal Issues in Children with Autism](#)

Wednesday, January 10, 1:00-2:00 pm ET

Autism Research Institute

Federal Threats to Health Care and Anti-Poverty Programs in 2018

Wednesday, January 10, 4:00-5:00 pm ET

Center for Budget and Policy Priorities

Working Effectively with Diverse Families of Children and Youth with Behavioral Health Challenges

Tuesday, January 23, 1:00-2:00 ET

Sponsored by the PACER Center

Adaptive Automotive Equipment Options for People with Spinal Cord Injuries

Wednesday, January 24, 2:30-3:30 pm ET

United Spinal Association

Increasing Health Care Access for Teens through Medicaid & CHIP

Wednesday, January 24, 3:00-4:00 pm ET

U.S. Department of Health and Human Services (InsureKids.gov)

You Shouldn't Have To Be a Rocket Scientist to Access Services for Kids with Disabilities

Wednesday, January 24, 3:00-4:00 pm ET

Family Voices of California

Chickasaw Nation Tackles the Opioid Epidemic

Thursday, January 25, 3:00-4:00 pm ET

The American Indian and Alaska Native (AI/AN) National Partnership for Action to End Health Disparities (NPA) Caucus

PAX (Good Behavior Game) Tools for Parent Peer Specialists

Tuesday, January 30, 12:00-1:00 pm ET

Sponsored by SAMHSA, developed under contract by the National Federation of Families for Children's Mental Health

CONGRESS

FY 2018 Appropriations and Other Issues

The current (2018) federal fiscal year began on October 1, 2017, but Congress still has not enacted appropriations bills to fund government functions. Since October 1, funding has come through two "continuing resolutions" (CRs), which have basically kept programs and agencies funded at last year's levels. A CR just enacted on Christmas will provide funding through January 19. One reason for the hold-up is the need to reach agreement on the relative levels of spending for defense and non-defense programs, which must be determined before specific appropriations bills can be passed. Tied to these negotiations are other issues, including disaster aid; immigration policies; and extensions of funding for the Children's Health Insurance Program (CHIP), community health centers, home visiting, and other "extenders" (including funding for Family-to-Family Health Information Centers). Since 60 votes will be needed in the Senate to pass appropriations bills and other legislation, bipartisan agreement will be needed. (Only 50 votes were needed to pass health care reform proposals and the tax bill because that legislation was considered under special budget reconciliation rules.) Once the overall spending levels

are agreed to, there will probably be another CR so that appropriations bills can be passed, but the aim is to have agreement on the other issues by January 19. Otherwise, there may be a government shut-down.

Immigration policy is one of the major matters to be settled. Republicans are seeking measures to restrict immigration and tighten border security, including perhaps the construction of a wall along the Mexican border. Democrats want legislation to extend the “Deferred Action for Childhood Arrivals” (DACA) program instituted by President Obama. (DACA allows unauthorized immigrants brought to this country as children, “Dreamers,” to get two-year permits to stay in this country. President Trump announced in September that DACA permits would begin to expire permanently as of March 5.) See [Trump, Lawmakers Step Up Talks on Immigrant “Dreamers”](#) (Reuters, 1/4/18).

CHIP – NEW DEVELOPMENTS

Reportedly, the House and Senate came to an agreement before Christmas on a bipartisan, five-year extension of CHIP funding, along with the “offsets” needed to pay for it. Yet, attempts to develop one big package addressing overall spending levels, immigration, and other major issues in a single package, have delayed enactment of legislation to extend funding for CHIP.

The CHIP program is jointly funded by the states and federal government, and the federal funding expired on September 30. Two temporary funding patches were enacted since then, the most recent of which was intended to provide sufficient federal funding to keep state programs running through March. The Centers for Medicare and Medicaid Services (CMS) has reported, however, that **some states may not be able to maintain the program beyond January 19 without additional federal funding**. See [CHIP funding was supposed to last through March. It could start to run out in 2 weeks](#) (Vox, 1/5/18); [Running On Empty: CHIP Funding Could Run Out Jan. 19 For Some States](#) (Kaiser Health News, 1/5/18).

Last week, the Congressional Budget Office (CBO) greatly reduced the cost estimate — from \$8.2 to \$0.8 billion (\$800 million) over 10 years — for the 5-year CHIP extension that was approved by the Senate Finance Committee, the Keep Kids' Insurance Dependable and Secure Act of 2017, or the KIDS Act of 2017. The basis for this change is the relatively lower cost of covering kids in CHIP compared to private Marketplace plans and Medicaid, as explained in a blog post from the Georgetown Center for Children and Families (CCF), [CBO Releases New CHIP Score](#) (1/5/18). **On Tuesday, it was reported that a 10-year CHIP extension would SAVE the federal treasury \$6 billion compared to current law**. This breaking development could change the scenario for CHIP funding.

Background: Nationwide, about nine million children rely on CHIP for their insurance coverage. If federal CHIP funding ends, states with CHIP incorporated into their Medicaid programs must keep kids covered, but will receive less funding than they do now to cover the CHIP population. States with free-standing CHIP programs could close or cut back their CHIP programs. For more information, see [Frequently Asked Questions about the Children’s Health Insurance Program \(CHIP\)](#) (National Academy for State Health Policy, updated 12/8/17; a very clear explanations of what states can do if CHIP funds run out); [Extending the Children’s Health Insurance Program: High Stakes for Families and States](#) (The Commonwealth Fund, Sept. 2017; good overview of the CHIP program and consequences of not funding it); [State Plans for CHIP as Federal CHIP Funds Run Out](#) (Kaiser Family Foundation, 12/6/17).

Family-To-Family Health Information Center (F2F) Funding

Federal funding for the F2F program expired on September 30. For grants to continue beyond May 2018, Congress must extend the program. A two-year extension may be included in a package to fund other “health extenders” along with CHIP. A House-passed bill would expand the program to US territories and tribes and increase its funding from \$5 to \$6 million annually. A Senate bill would only provide a simple extension. See the [November 8 Update](#) for more details.

RAISE Family Caregiver Act

From the National Respite Coalition Legislative Alert, 1/9/18

On January 8, 2018, the Senate passed the *Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2017 Act* ([H.R. 3759](#)). The House had passed the bill in December. The legislation, originally introduced in the Senate by Senators Susan Collins (R-ME) and Tammy Baldwin (D-WI) and in the House by Representatives Gregg Harper (R-MS) and Kathy Castor (D-FL), would provide for the establishment of a Family Caregiving Strategy to be developed by the Secretary of Health and Human Services in consultation with heads of other federal agencies and an Advisory Council. The Strategy will identify recommended actions that existing Federal programs, State, and local governments, communities, health care providers, long-term services and supports providers, and others are taking, or may take, to recognize and support family caregivers in a manner that reflects their diverse needs, including the need for respite options. The bill will now go to the President for his signature.

Changes in Senate Membership

In a 1939 movie, a fictional Mr. Smith went to Washington. In 2018, it was a real Ms. Smith – Tina Smith (D) from Minnesota. There are now 22 female Senators out of 100, a record high. Ms. Smith replaced Senator Al Franken (D), who had resigned. Sworn in the same day was Mr. Jones – Doug Jones (D) of Alabama, the first Democratic Senator elected from that state since 1992. (The last was Richard Shelby, still a Senator but now a Republican.) Mr. Jones replaced Senator Jeff Sessions (R), now the Attorney General. The election of Mr. Jones reduced the Republican majority by one seat, so that there are now 51 Republicans and 49 Democrats. In the Senate, a one-seat change is significant, given how close some important votes are.

Another notable change in Senate membership will occur after this session, as Senator Orrin Hatch (R-UT), the longest serving Senate Republican, announced that he would not run for reelection this year. Senator Hatch is the chairman of the Senate Finance Committee, which has jurisdiction over Medicare, Medicaid, much of the Affordable Care Act, and Family-to-Family Health Information Centers. Assuming the Republicans are still in the majority, the next in line to be Finance Committee Chairman would be Senator Chuck Grassley (R-IA), who has previously served in that position. If he should choose instead to remain as chair of the Judiciary Committee, Senator Crapo (R-ID) would be next in line for the Finance chairmanship. If the Democrats take over the Senate, Senator Wyden (D-OR) would be in line for the chairmanship.

FROM THE EXECUTIVE BRANCH

Proposed Regulation Affecting Health Insurance

On January 5, the U.S. Department of Labor (DOL) released a proposed rule to facilitate the expanded use of “association health plans” (AHPs). See [press release](#); [text of proposed regulation](#) (note link to

PDF on the right). Such plans would be exempt from the essential health benefits and some of the consumer protections mandated by the Affordable Care Act (ACA). Thus, AHPs could offer cheaper, bare-boned health policies, removing healthier individuals from the individual and small-group insurance risk pools. Consequently, insurance premiums would likely rise for [people with pre-existing conditions](#) and others who want more robust benefits. While AHPs would not be permitted to turn away or charge more for people with pre-existing conditions, they could set rates on factors such as geographic area and the type of industry in which an employer works, allowing them to indirectly exclude the people most likely to use health care. See [Trump Administration Rule Paves Way for Association Health Plans](#), Kaiser Health News (1/4/18); [Trump administration rolls out health plan rules that could weaken Obamacare](#), Politico (1/4/18). Comments can be submitted [here](#) (same link as to register; upper right-hand corner of page). They are due on or before March 6, no later than 11:59 pm ET.

SAMHSA Final Rule on Confidentiality of Substance Abuse Records

On January 3, the Substance Abuse and Mental Health Services Administration's (SAMHSA) issued a [final rule](#), effective on February 2, 2018, regarding the confidentiality of substance use disorder patient records. Background on the issue can be found [here](#).

ADA Guidance on Employment Systems Withdrawn

On December 21, the Department of Justice [announced](#) that it had withdrawn its October 2016 guidance on State and local governments' employment service systems, titled "Statement of the Department of Justice on Application of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.* to State and Local Governments' Employment Service Systems for Individuals with Disabilities."

YOUR INPUT SOUGHT

NEW: Transition for Youth Receiving SSI

Deadline: Friday, February 2, 2018

On January 3, the Social Security Administration (SSA) issued a [Request for Information \(RFI\) on Strategies to Improve Adult Outcomes for Youth Receiving Supplemental Security Income \(SSI\)](#). The agency seeks public input on strategies for improving the adult economic outcomes of youth ages 14 to 25 with disabilities receiving SSI," and notes that the input received will inform deliberations about potential policy changes and the design of future demonstration projects for transition-age SSI recipients. The agency poses a number of specific questions to prompt feedback.

Department of Justice Withdraws Guidance from ADA Website

The Department of Justice has withdrawn and removed from ADA.gov its October 2016 guidance on State and local governments' employment service systems, titled "Statement of the Department of Justice on Application of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.* to State and Local Governments' Employment Service Systems for Individuals with Disabilities." This action was taken to afford further discussion with relevant stakeholders, including public entities and the disability community, as to how best to provide technical assistance in this area. Withdrawal of this guidance document does not change the legal responsibilities of State and local governments under title II of the ADA, as reflected in the ADA, its implementing regulations, and other

binding legal requirements and judicial precedent, including the U.S. Supreme Court's *Olmstead* decision. This withdrawal should not be understood as expressing any view on the legal merits of the principles set forth in this Statement, or on the merit of any specific procedures currently in place in any State or local jurisdictions. The Department will continue to fully and fairly enforce all laws within its jurisdiction, including the ADA.

CALL FOR SUBMISSIONS: AcademyHealth Annual Research Meeting

Deadline: Thursday, January 11, 2018, at 5:00 pm ET

The AcademyHealth Annual Research Meeting (June 24-26, 2018; Seattle, Washington), provides an opportunity to share the "family voice." The meeting typically convenes more than 2,600 health policy and health services researchers and policy staffers to learn about new research, discuss policy implications, sharpen skills, and network with colleagues from around the world. It provides a forum for disseminating evidence that can help policymakers, clinicians, and executives improve our health system. [Here's the link to information on how/what to submit.](#)

CDC Calls for AI/AN Public-Health Success Stories

Deadline: January 15, 2018

The Centers for Disease Control and Prevention (CDC) is inviting the public to share stories illustrating how tribal communities contribute to public health, and how tribal cultures have fostered health and wellness among American Indians/Alaska Natives (AI/AN). The stories will be part of a new exhibit at the [David J. Sencer CDC Museum](#) in Atlanta, GA, to be held from Sept 22, 2019, through May 1, 2020. The exhibit will recognize the public health contributions of the AI/AN community, showcasing the ways that native traditions and wisdom have affected public health in the past and present, and how AI/AN communities have made a difference in the health of their people. CDC is interested in stories that highlight how native traditions and wisdom have affected health or show contributions of specific AI/AN individuals to health and wellness among AI/AN people. [Click here for more information and instructions](#) for submitting stories.

Speakers Needed for January Webinar on Preventing Injuries among CYSHCN

Family Voices has been contacted by the [Children's Safety Network](#) (CSN), which is requesting help in planning a January 2018 webinar focused on preventing injuries among children and youth with special health care needs. The webinar audience is usually a mix of local, state, and national-level professionals who are planning or implementing injury prevention programs. The CSN is looking for webinar presenters, and would pay a stipend to one or two parent leaders who would be willing to speak. If you are interested, please contact Cindy Rodgers at CSN, crodgers@edc.org, 617-291-4023.

[Research Project on Perception of Caregivers](#)

Deadline: March 2018

When people hear that you are a caregiver, what do they tell you? This project will explore how people in the general population view caregivers through a 10-minute survey. The research is being conducted as part of a Dissertation Research project in the Department of Psychology and Neuroscience at the University of North Carolina, Chapel Hill. The study seeks to recruit 2,000 caregivers by March 2018. Learn more and participate [here](#).

OF POSSIBLE INTEREST

[A Baby Girl, Ready to Go Home, Is Still in the Hospital 400 Days Later](#), Bloomberg News (1/8/18).
(Family Voices Executive Director Nora Wells is quoted.)

[Virtual calming – Easing Anxiety in Young Patients using Immersive Technology](#), Stanford Medicine
(Fall 2017).

NPR Series on Abuse of People with Intellectual and Developmental Disabilities. The series schedule is as follows:

- **Jan 8: Morning Edition:** Correspondent Joe Shapiro talks about the series with host Steve Inskeep.
- **Jan 8: All Things Considered:** [The epidemic of sexual abuse of people with intellectual disability](#). Numbers obtained by NPR show they are sexually assaulted at rates more than 7 times those for all adults without disabilities.
- **Jan 9: Morning Edition:** A visit to a Sex Ed class for people with intellectual disability. They talk about how they want relationships, but how the sexual violence of their past often gets in the way.
- **Jan 10: All Things Considered:** On cases that go unnoticed when people have difficulty communicating.
- **Jan 16: All Things Considered:** Police and prosecutors are often reluctant to take these cases. NPR goes back to Essex County, New Jersey, where the first case to get widespread attention--in Glen Ridge, New Jersey, 25 years ago--was prosecuted. And look at what prosecutors have learned since.
- **Jan 18: Morning Edition:** Therapists Nora Baladerian and Karyn Harvey talk about the stunning violence in the lives of their clients.
- **Jan 18: All Things Considered:** Self-advocates speak of the effects of sexual violence. This piece is entirely in the voices of people with intellectual disability (plus Joe Shapiro).

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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

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