



FAMILY VOICES[®]

Washington DC Update SPECIAL EDITION!
February 9, 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.

Check out a new resource from the National Center for Family Professional Partnerships:
[Promising Practices in Cultural Competence.](#)

Greetings from Washington! In the wee hours of Friday morning, the Senate, followed by the House, passed a bill to set spending levels for the next two years and to keep the government open through March 23. The president signed the bill at about 8:30 AM. The new law **includes a two-year extension of funding for Family-to-Family Health Information Centers, with a \$1 million increase and an amendment to require that F2Fs be established in the US territories and for at least one Indian tribe.** In addition, it includes additional funding for the Children's Health Insurance Program (CHIP), so that CHIP funding is now provided for another 10 years, through 2027. It also includes Medicaid funding for Puerto Rico and the US Virgin Islands, disaster relief funding, a five-year extension of funding for the home visiting program, money to combat the opioid crisis, additional funding for child care, and measures intended to improve the child welfare system. The law does NOT provide funding to address border security ("the wall") or to address the situation of "DREAMers," the young adults who were brought to this country illegally as children. See [Trump signs budget deal ending shutdown](#) (The Hill, 2/9/18).

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UPCOMING WEBINARS AND CALLS (ALL TOPICS)

[An Inside Look at DHH Mentor, Guide, and Role Model Services in EHDI* and Beyond](#)

Friday, February 9, 1:00-2:00 pm ET

National Center for Hearing Assessment and Management and Hands & Voices

*Early Hearing Detection and Intervention

NEW [Take Command of Your Health: New Year, New TRICARE](#)

Monday, February 12, 1:00 PM-2:00 pm ET

Military OneSource

NEW The Trump Budget: What You Need to Know

Wednesday, February 14, 12:30-1:30 pm ET

Co-sponsored by the Coalition on Human Needs, Center on Budget and Policy Priorities, Center for American Progress, and the Food Research & Action Center.

[About administration's proposed budget for FY 2019, expected to be released 2/12]

The Opioid Crisis: Understanding Pain and Preventing Opioid Misuse

Tuesday, February 13, 1:00-2:30 pm ET

National Institute for Health Care Management (NIHCM) Foundation

Advance Planning for Independence and Autonomy

Thursday, February 15, 9:00-10:00 am ET

University of Albany School of Public Health

Linking Medical Homes to Social Service Systems for Medicaid Populations | Research in Progress Webinar

Wednesday, February 21, 12:00-1:00 pm ET

Systems for Action National Coordinating Center

NEW Home- and Community- Based Services (HCBS) Quality Measurement Tools

Wednesday, February 21, 2:00-3:00 pm ET

Centers for Medicare and Medicaid Services (CMS)

Criminal Justice, the Americans with Disabilities Act, and People with Mental Illnesses

Monday, February 26, 2018 2:30-4:00 pm ET

Substance Abuse and Mental Health Services Administration (SAMHSA) and National Association of Mental Health Program Directors

NEW Innovations in Medicaid Managed Long-Term Services and Supports: How Health Plans are Providing Support to Family Caregivers

Wednesday February 28, 1:00-2:00 pm ET

Health Management Associates and the AARP Public Policy Institute

NEW Aligning Services with Needs: Complexity Tiering for Children with Chronic and Complex Conditions

Wednesday, February 28, 2:00-3:00 pm ET

Lucile Packard Foundation for Children's Health, Catalyst Center, Family Voices

NEW DATE & TIME Marketplace Appeals Process

Thursday, February 28, 2:30-3:30 pm ET (was Feb. 1 at noon ET)

Note: No need to register again if you were registered for the original date.

Health Reform: Beyond the Basics (Center on Budget and Policy Priorities)

Direct Connect Learning Community - Making Data Work for You: Part 2

[Virtual forum for youth and young adults]

Wednesday, February 28, 3:30-5:00 pm ET

Youth M.O.V.E. and SAMHSA

CONGRESS

The Continuing Saga – Funding the Federal Government (and Family-to-Family Health Information Centers)

Federal fiscal year 2017 began on October 1, 2017, but Congress has not passed the appropriations bills needed to fund the departments, agencies, and discretionary programs of the government (as opposed to mandatory programs like Social Security, Medicare, and Medicaid, which are not funded through appropriations). Instead, several temporary funding measures (“continuing resolutions,” or CRs) were enacted. Most recently...

On January 22: A CR was enacted to keep the government running through February 8. The significant things about that agreement:

- It included a six-year extension of CHIP funding.
- In order to get the Democratic support needed to pass the bill, Senate Majority Leader Mitch McConnell (R-KY) promised that the Senate would openly debate and hold a vote on legislation -- referred to as DACA (for Deferred Action on Childhood Arrivals) -- to address the situation of “DREAMers” (youth brought into this country illegally as children), *if* the Democrats would agree to another CR if necessary.

February 6: The House passed another CR which would, among other things:

- Fund the Defense Department for the remainder of the fiscal year;
 - Fund the other agencies through March 23;
 - Fund community health centers for two more years;
- AND
- **Fund Family-to-Family Health Information Centers** through FY 2019 at an increased level (\$6 million, up from \$5 million), and create F2Fs for territories and Indian tribes.

February 7: Congress passed and the president signed a bill which will: Increase spending caps for both defense and [non-defense programs](#) over the next two years, meaning there will not need to be significant cuts in many of programs important to children, families, and people with disabilities.

- Fund all agencies through March 23, at which point there should be a bill to fund agencies for the remaining 6 months of the fiscal year;
- As in the House bill, fund **Family-to-Family Health Information Centers** for two more years (through FY 2019) at an increased level (\$6 million, up from \$5 million), and create F2Fs for territories and Indian tribes;
- Fund **CHIP** for an additional four years, for a total of 10 more years of funding, through 2027.
- Fund **community health centers** for two more years;
- Fund the Maternal, Infant, and Early Childhood **Home Visiting** program for five more years;
- Fund disaster relief efforts for Puerto Rico, the U.S. Virgin Islands, Florida, and Texas, including almost \$5 billion to increase Medicaid caps for Puerto Rico and U.S. Virgin Islands for two years;
- Provide \$6 billion over two years to address **opioid** addiction;
- Provide \$2 billion in funding over two years for the **National Institutes of Health**;
- Provide \$5.8 billion for **child care** over two years; and
- Lift the debt limit through March 1, 2019.

In addition, the bill includes the “[Family First Prevention Services Act](#),” intended to improve the child welfare system and reduce the need for foster-care placements.

Many fiscally conservative Republicans (and some Democrats) opposed the bill because it increases the deficit significantly. See [The House Staring Contest: Pelosi and Ryan](#) (Roll Call, 2/7/18). The legislation does include some “pay-fors,” however, including a **cut to the Prevention and Public Health Fund**, which is likely to reduce funding for the Centers for Disease Control and Prevention (CDC), and some changes in third-party liability for Medicaid that could hurt providers.

[DREAMers and DACA/border security](#). Notably, the new law does **NOT** include “DACA” (Deferred Action on Childhood Arrivals) legislation to address the future of young people brought to this country illegally as children (“DREAMers”). House Minority leader Nancy Pelosi (D-CA), among others, opposed the bill because House Speaker Paul Ryan (R-WI) did not explicitly promise to hold a House vote on some version of bipartisan DACA legislation. See [House Democrats Divided on Backing Budget Deal Without DACA](#) (Roll Call, 2/7/18). Nor did the bill include any measures to address other immigration policy or border security, which the president wanted. Pursuant to the promise he made in January, though, Senator Majority Leader Mitch McConnell has scheduled [open debate on this issue](#) on the Senate Floor next week.

More information:

Continuing Resolution Summary: <https://www.appropriations.senate.gov/download/continuing-resolution-summary>

Disaster Relief Summary:

<https://www.appropriations.senate.gov/download/supplemental-appropriations-summary>

Legislative Text:

<https://www.appropriations.senate.gov/download/bipartisan-budget-act-of-2018-text>

The ADA Education and Reform Act of 2017

Next week the House is expected to take up the “ADA Education and Reform Act of 2017” ([H.R. 620](#)). Although the bill is bipartisan, it is opposed by many disability advocates because it would weaken the Americans with Disabilities Act (ADA). The bill would eliminate the requirement that businesses and other entities be accessible unless a complaint is filed against them, make the complaint process more burdensome, and give businesses more time to address ADA violations. The Judiciary Committee’s report on the bill ([House Report 115-539](#)) includes dissenting views (pp. 17-27) which discuss these concerns.

“Right to Try” Legislation

In his recent State of the Union speech, the president stated his support for “Right-to-Try” legislation, which would permit terminally ill patients to try treatments not yet approved by the Food and Drug Administration (FDA). On February 6, forty patient advocacy groups sent a [letter](#) to the Hill expressing their opposition to the particular legislation under consideration. This legislation was approved by the Senate, and a modified version of it may be taken up fairly soon in the House. See [40 Patient Advocacy Groups Oppose 'Right To Try' Drug Bill](#) (The Hill, 2/6/18).

Drug Pricing Legislation

On February 6, 44 groups which generally have diverging interests, signed a [joint letter](#) to congressional leaders to urge passage of the bipartisan “Creating and Restoring Equal Access to Equivalent Samples (CREATES) Act ([S. 974/H.R. 2212](#)). The legislation is intended to lower prescription drug prices by preventing manufacturers of brand-name drugs from taking measures to delay marketing of equivalent generic drugs. See [Coalition of 44 groups calls for passage of drug pricing bill](#) (The Hill, 2/6/18)

In lighter news: [\[Senator Angus King of Maine\] Announces Lobster Emoji Officially Coming Soon](#)

MEDICAID NEWS, INFORMATION AND RESOURCES

Indiana Waiver Approved

On February 2, the Centers for Medicare and Medicaid Services (CMS) [approved](#) a Medicaid waiver request from Indiana. Like the recently approved Kentucky waiver, the Indiana waiver will require some Medicaid beneficiaries to work as a condition of eligibility. If they fail to document that they are meeting the work requirements, they can be denied coverage for three months. See [Indiana Gets Federal Approval For Medicaid Plan That Could Slice Enrollment](#) (Kaiser Health News, 2/2/18); [Indiana Wins Federal Permission To Adopt Medicaid Work Requirements](#) (Washington Post, 2/2/18).

For more information on work requirements and other waiver components, see:

- [State Proposals for Medicaid Work and Community Engagement Requirements](#) (National Academy for State Health Policy, updated periodically) -- status of waiver requests
- [Understanding the Intersection of Medicaid and Work](#) (Kaiser Family Foundation Issue Brief, 1/5/18)
- [Work Requirements May Be Just the Beginning of Medicaid Changes Under Trump](#) (Governing, 1/12/18)
- [Are Work Requirements for Medicaid Doomed?](#) (Governing, 1/25/18)

OTHER NEWS, INFORMATION AND RESOURCES

[CDC Resources on the Flu](#)

The CDC’s [seasonal flu vaccination campaign materials](#) are available to assist partners in communicating about the importance of vaccination, and includes a digital toolkit with web-ready resources and social media. The CDC [free resources](#) section hosts a variety of materials, [including podcasts and PSAs, videos, infographics, and print materials](#). See also [Prompt Use of Antivirals is Key this Flu Season](#).

[Find Tools to Start your Health Literacy Research Today!](#) (CDC)

Includes information on Identifying opportunities and barriers to improving health literacy in your organization and resources on our site to improve the effectiveness of your communication and program activities. Also see the CDC [Clear Communication Index](#) site and the [Federal Plain Language Guidelines](#).

[Report Examines 6 State Initiatives Aimed to Improve Care for Vulnerable Children Through Interagency and Cross-Sector Collaboration](#) (Health Management Associates for the Lucile M. Packard Foundation for Children, 2/7/18)

TRICARE

Article: [Reduced Costs for Certain Diabetes, High Cholesterol Drugs](#)

Webinar: [Take Command of Your Health: New Year, New TRICARE](#), sponsored by Military OneSource, Monday, Feb. 12, 1:00 - 2:00 pm ET.

WORTH REPEATING: [Resources to Help You Understand Your Benefit](#)

YOUR INPUT SOUGHT

Proposed Rule on Conscience Rights in Health Care

Comments due March 27

On January 19, 2018, the HHS Office for Civil Rights (OCR) issued a [proposed rule](#) to amend existing “conscience” regulations and broaden the scope of OCR oversight. The agency’s aim is to ensure that health care providers are not required to provide services (e.g., abortions) that conflict with their religious or moral beliefs. Some patient and civil liberties advocates are concerned that the rules may permit health care providers to discriminate against people based on gender identity or sexual orientation. See [New HHS civil rights division charged with protecting health-care workers with moral objections](#) (Washington Post, 1/18/18); [Trump Administration Prioritizes Religious and Moral Exemptions for Health Care Workers](#) (Health Affairs Blog, 1/21/18). Public comments can be submitted through March 27 at <https://www.regulations.gov/comment?D=HHS-OCR-2018-0002-0001>.

[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

[From Insight to Advocacy: Addressing Family Caregiving as a Public Health Issue](#)

[Mothers Mentoring Mothers](#)

[Tackling Health Barriers to Learning – Does Your State Mandate Student Health Screenings?](#)

[California's lack of early health screening for children delays proper treatment](#)

[Why Don't You Hear More About Sickle Cell Disease? \(listen\)](#)

Family Voices, Inc. • Mailing Address: P.O. Box 37188, Albuquerque, NM 87176 • Physical Address: 3701 San Mateo Blvd NE, Suite 103, Albuquerque, NM 87110 • Phone: 505-872-4774 • Toll Free: 888-835-5669 • Fax: 505-872-4780 • Website: www.familyvoices.org

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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