



FAMILY VOICES[®]

Washington DC Update
February 27, 2019

GREETINGS FROM WASHINGTON!

Members of Congress have been busy recently, launching an investigation into insulin prices; holding a hearing on prescription drug prices and another on restraint and seclusion; and writing to the Secretary of HHS about Medicaid waivers. In other news, the 2016-2017 National Survey of Children's Health (NSCH) is now available. Read about these news items, and find resources on preparing for emergencies and more, in this week's Update.

February is **Black History Month**. Visit the [Black History Month](#) webpage of the HHS Office of Minority Health for materials, upcoming events, and health resources.

SAVE THE DATE! 2019 Family Leadership Conference, May 8-10, Washington, DC, "Families as Partners Shaping Systems Change."

JOIN US! The 2019 Family Voices Leadership Conference will bring together a diverse community of family and youth leaders, family members, professional partners, and other stakeholders from across the country. Together we will learn from each other, share resources and expertise, explore ways to improve supports to families, learn new strategies for managing nonprofits, and increase capacity for families to partner in systems change. Watch the [Family Voices Conference Web Page](#) for more information!

Registration opens Friday! For more information, click [here](#).

UPCOMING WEBINARS AND CALLS

[Starting and Sustaining a Youth Advisory Board, Part 1: Youth Voice](#)

Wednesday, February 27, 12:00-1:00 pm ET

Family Voices

This webinar series is especially for organizations that seek to develop a youth advisory board.

Communication for a Nuclear or Radiological Disaster

Wednesday, February 27, 1:00 pm ET

CDC's Emergency Partners Information Connection (EPIC)

Please click the link below to join the webinar:

<https://zoom.us/j/980304069>

Or Dial (for higher quality, dial a number based on your current location):

US: +1 646 876 9923 or +1 669 900 6833

Webinar ID: 980 304 069

2019 State Paths to Better Health Care

Wednesday, February 27, 2:00-3:00 pm ET

Families USA

Debunking the Three Biggest Myths about Disability Benefits and Work

Wednesday, February 27, 3:00-4:30 pm ET

Social Security Administration

Understand the Business Environment and Your Place within It

Thursday, February 28, 12:30-1:30 pm ET

HCBS Business Acumen Center

Holistic Health and Sickle Cell Disease: A Focus on Mental and Behavioral Health

Thursday, February 28, 1:00-2:15 pm ET

HHS Office of Minority Health

Strategies for Funding an ABLE Account

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

ABLE National Resource Center

Special Enrollment Periods

Thursday, February 28, 3:00 pm ET

Center on Budget and Policy Priorities (CBPP)

SERIES: Pain Medication Education

Christopher and Dana Reeve Foundation

- **Part 3: What are my options for tapering opioids?**
Wednesday, March 13, 12:00-1:00 pm ET
- *Past -- Part 1: "What is my pain medication?" [Video](#); [Info](#).*
- *Past -- Part 2: Understanding Opioids and Opioid Addiction*

SERIES: Learning and Reflection Forum Series

Leadership Institute for Cultural Diversity and Cultural and Linguistic Competence

To discuss challenges and opportunities associated with leading cultural diversity and cultural and linguistic competence within developmental disability agencies.

How We are Leading: Voices from Alumni

Thursday, March 14, 2:00-3:30 pm ET

Save the dates:

April 11, 2019 - 2:00-3:30 pm ET

Leading through Conflict: Overcoming Resistance

May 16, 2019 - 2:00-3:30 pm ET

To Be Determined (TBD)

June 13, 2019 - 2:00 pm-3:30 pm ET

Benchmarks, Measures & Frameworks at the Intersection of Cultural and Linguistic Competence and Disability

THE COURTS

[Judge Considers Expanding Child Separation Case](#)

(Associated Press, 2/21/19)

CONGRESS

Pallone, Wyden Call on Administration to Stop Allowing Harmful Medicaid Waivers

On February 19, House Energy & Commerce Committee Chairman Frank Pallone (D-NJ) and Senate Finance Committee Ranking Democratic Member Ron Wyden (D-OR), sent a [letter](#) to Department of Health and Human Services (HHS) Secretary Alex Azar about waivers that impose restrictions on Medicaid eligibility. The letter asserts that these waivers “undermine access to health care and violate the plain text and purpose of Title XIX of the Social Security Act and Congress’s longstanding intent for the Medicaid program.” In addition, the letter says that “new evidence indicates that the Administration is failing to appropriately track or evaluate the impact of these misguided policies.” In conclusion the authors urge the Secretary “to put a halt to any and all Section 1115 demonstration requests that jeopardize the health and financial security of millions of low-income Americans.” See the [Pallone press release](#); [Top Democrats Rebuke Trump Administration for Medicaid Work Requirement Policies](#) (CNN, 2/22/19).

Hearing on Restraint and Seclusion

A hearing titled [Classrooms in Crisis: Examining the Inappropriate Use of Seclusion and Restraint](#) has been scheduled for February 27 before the Subcommittee on Early Childhood, Elementary, and Secondary Education of the House Education and Labor Committee. The hearing relates to the expected reintroduction of a bill from the last Congress, the *Keeping All Students Safe Act* (115th Congress [H.R.7124](#) and [S.3626](#)). A live-stream of the hearing will begin at 10:00 am ET on the [committee website](#).

Hearing on Drug Pricing

On February 26, the Senate Finance Committee held a hearing on prescription drug pricing, with witnesses from seven major pharmaceutical manufacturers. See the [committee website](#) for a recording of the hearing, witness list, and statements from Chairman Chuck Grassley (R-IA) and Ranking Democrat Ron Wyden (D-OR). See also [‘It’s Finally Pharma’s Turn’: Drug CEOs Face Capitol Hill Reckoning](#) (Politico, 2/25/18). Also interesting: [Talk About Déjà Vu: Senators Set to Re-Enact Drug Price Hearing of 60 Years Ago](#) (Kaiser Health News (2/22/19)); [‘A Dark and Elaborate Art’: How Pharma Executives Are Training to Avoid Disaster at Tuesday’s Congressional Grilling](#) (STAT, 2/25/19).

Insulin Investigation

In related news, last Friday, Chairman Grassley and Ranking Member Wyden launched an investigation into the price of insulin. As explained in the [committee press release](#), they sent letters to leading insulin manufacturers Eli Lilly, Novo Nordisk, and Sanofi asking for specific information regarding recent price increases for insulin, including the process used to determine list and negotiated prices; the cost of research and development, production, marketing and advertising; profits; and the companies’ funding of patient-assistance programs and third-party tax-exempt organizations. See,

[Drug Pricing Fight Centers on Insulin](#) (The Hill, 02/20/19); ([Powerful Senate Committee Launches Bipartisan Probe Into Insulin Pricing](#) (STAT, 2/22/19).

Palliative Care and Hospice Education and Training Act Introduced

The bipartisan *Palliative Care and Hospice Education and Training Act* ([H.R. 647](#)) has been re-introduced in the House by Representatives Eliot Engel (D-NY), Tom Reed (R-NY), Yvette Clark (D-NY), Buddy Carter (R-GA), Frank Pallone (D-NJ), and Greg Walden (R-OR), and now has over 100 cosponsors. The bill would expand and promote palliative care and hospice research, education, and training, and would institute a campaign to raise national awareness for palliative care. In the last Congress, similar bills were introduced in the House and Senate. The Senate bill was introduced by Sen. Tammy Baldwin (D-WI) and garnered 56 cosponsors (a majority of the Senate.) The Hospice Action Network has prepared a [summary](#) of the legislation.

House Passes Bipartisan Poison Control Bill

On February 25, the House passed the bipartisan Poison Center Network Enhancement Act of 2019 ([H.R. 501](#)) by voice vote. The bill, which would reauthorize the national network of Poison Control Centers, has not yet been acted upon in the Senate.

WORTH REPEATING: ACE Kids Act Introduced in the House and Senate

During the last Congress, the *Advancing Care for Exceptional Kids Act* (ACE Kids Act) was passed by the House as part of a larger bill, but did not make it to the Senate. Since it is a new Congress, all legislation must be reintroduced. On February 4, Senators Chuck Grassley (R-IA) and Michael Bennet (D-CO) introduced the *Advancing Care for Exceptional Kids Act of 2019* ([S. 317](#)), and have since been joined by [cosponsors](#) from both sides of the aisle. A similar bill ([H.R. 1226](#)), also bipartisan, was reintroduced in the House by Representatives Kathy Castor (D-FL), Gus Bilirakis (R-FL), and Jaime Herrera Beutler (R-WA), and subsequently cosponsored by Rep. Joe Neguse (D-CO). The ACE Kids Act would amend Medicaid law to let states provide coordinated care for children with complex medical conditions through a health home, and would facilitate the provision of care across state lines. See the [Children's Hospital Association Press Release](#).

MEDICAID/CHIP NEWS, INFORMATION, AND RESOURCES

MEDICAID WAIVERS

Advocates and Healthcare Providers File Brief in Case Challenging the Kentucky Medicaid Waiver

As reported in previous Updates, the administration has been supportive of waivers to establish “community-engagement” (work, education) requirements on Medicaid beneficiaries. See [1115 Community Engagement Initiative](#) on the Centers for Medicare and Medicaid Services (CMS) website [Medicaid.gov](#). CMS has approved several such waivers in various forms, some of which have been challenged in court. A federal district court invalidated the Kentucky waiver, remanding it to the Department of Health and Human Services (HHS) for reconsideration. After the administration reapproved the waiver in November 2018, the approval was challenged again in court. In January, an [amicus \(friend-of-the-court\) brief](#) was submitted by the American Academy of Pediatrics,

American College of Physicians, the American Medical Association, American Psychiatric Association, Catholic Health Association of the United States, March of Dimes, and National Alliance on Mental Illness. As explained in [Health Care Providers, Advocates Explain Harm of Medicaid Work Requirements](#) (blog post from the Center on Budget and Policy Priorities, 2/21/19), the *amicus* brief argues that work requirements can harm Medicaid beneficiaries in several ways.

WORTH REPEATING: Updated 1915(c) Waiver Application

On January 28, 2019, CMS released a revised application and technical guide for Medicaid 1915(c) waivers, used to provide home-and community based services. According to this [information provided by the National Association of States United on Aging and Disabilities](#), the application includes some notable additions and modifications including:

- A request for information about whether the state administers any quality of life/quality of care surveys of waiver participants, such as the NCI or NCI-AD surveys; and
- Updates to several sections to reflect recent guidance and policy developments, including the sections on public input and self-direction.

View the [updated waiver instructions](#).

View the updated [waiver application form](#).

MEDICAID RESOURCES

WORTH REPEATING: The Kaiser Family Foundation has released a new brief, [Section 1115 Medicaid Demonstration Waivers: The Current Landscape of Approved and Pending Waivers](#). The brief discusses some of the newer elements of Medicaid waivers, including “community-engagement” (work, etc.) requirements, substance-abuse initiatives, and the use of Medicaid to pay for services to address the social determinants of health (a North Carolina pilot program to address housing instability, transportation, food insecurity, and interpersonal violence and toxic stress).

REMINDER:

- Approved and pending Medicaid waiver applications can be found on [Medicaid.gov](#).
- The Kaiser Family Foundation regularly updates its state-by-state §1115 [Medicaid Waiver Tracker](#), and also provides related waiver [resources](#) and [definitions](#).

AFFORDABLE CARE ACT

Need to Submit Documents to Confirm a Life Event?

(Healthcare.gov blog, 2/7/19)

OTHER NEWS, INFORMATION, AND RESOURCES

FROM THE AGENCIES:

Emergency Planning Toolkit for Aging and Disability Networks

The new [Capacity-Building Toolkit for Including Aging and Disability Networks in Emergency Planning](#) (PDF, 114 pp), is intended to help aging and disability networks increase their ability to plan for and

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respond to public health emergencies and disasters. It was written by the National Association of County & City Health Officials and the Association of State and Territorial Health Officials, in partnership with the HHS Office of the Assistant Secretary for Preparedness and Response, and the Administration for Community Living (ACL). The toolkit is can be used by both those new to emergency planning and those with established emergency preparedness programs.

Other Resources to Help With Emergency Planning For People with Disabilities:

From ACL:

- An [emergency information card](#) (PDF, 1 p) that patients or caregivers can download and customize with information about the cardholder's disability.

From the CDC:

- [State emergency-preparedness tools and resources](#) for people with disabilities, caregivers, emergency planners, first responders, and other community members.
- [Webinar slides](#) (PDF, 1.7 MB, 33 pp) and [transcript](#) from a November 2018 webinar, "Addressing the Needs of People with Disabilities in Public Health Emergencies."

FROM FAMILY VOICES:

[Building Partnerships and Educating Families and Professionals about Supported Decision Making](#) – the recording and slides from the February 21, 2019, *Family Voices and Quality Trust* webinar are now available.

FROM FAMILY VOICES PARTNER ORGANIZATIONS:

ABLE National Resource Center: [Top Three Questions - Feb. 2019](#)

Child and Adolescent Health Measurement Initiative: National Survey of Children's Health

The Data Resource Center (DRC) for Child and Adolescent Health, in collaboration with the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB), has released the combined 2016-2017 National Survey of Children's Health (NSCH) data sets and codebooks, available at childhealthdata.org. The combined 2016-2017 NSCH is the first multi-year data set since the redesign of the NSCH in 2016, and includes data from over 71,000 children ages 0-17 years. Single year 2017 NSCH data findings, downloadable data sets, and codebooks will be available through the DRC in Spring 2019. For more information and resources on the NSCH, see the [DRC NSCH Overview page](#). More resources are available at [HRSA MCHB's webpage on the NSCH](#). Public use files for the 2016 NSCH and 2017 NSCH are also available through the [U.S. Census Bureau's NSCH page](#). For more information, contact info@cahmi.org.

YOUR INPUT SOUGHT

NEW FEMA National Advisory Council – Due March 15, 2019

The Federal Emergency Management Agency (FEMA) is accepting applications until March 15, 2019, for 12 open positions on its National Advisory Council. They are seeking one person to fill the slot called "*Disabilities, Access and Functional Needs.*" This person must be in a position to represent one or more of these groups: *individuals with disabilities*, older adults, and individuals with limited English

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proficiency, access to transportation, and/or access to financial resources to prepare for, respond to, and recover from an emergency. For more information see the [Membership Application Information and Instructions](#) (also in [PDF](#)).

NEW SNAP Work Requirements – Due April 2, 2019.

Earlier this month, the U.S. Department of Agriculture announced a [proposed rule](#) that would enforce time limits on SNAP (food stamp) benefits for individuals who do not document sufficient weekly work hours. Comments are due April 2, 2019.

[Pain Management Task Force Draft Report – Due April 1, 2019](#)

The Comprehensive Addiction and Recovery Act of 2016 (CARA), requires that the public be given at least ninety (90) days to submit comments on any proposed updates and recommendations developed by the [Pain Management Best Practices Inter-Agency Task Force](#) (Task Force). The Task Force is requesting comments on its [Pain Management Best Practices: Updates, Gaps, Inconsistencies, and Recommendations](#) ([PDF](#)), which includes sections on [Unique Issues Related to Pediatric Pain Management](#); [Sickle Cell Disease](#); and [Health Disparities in Racial and Ethnic Populations, Including African-Americans, Latinos, American Indians, and Alaska Natives](#). [Submit comments.](#)

Electronic Health Information – due early April

On Monday, February 11, 2019, the Centers for Medicare & Medicaid Services (CMS) released a [proposed rule](#) intended to facilitate the use of electronic health information and promote patient access to and control over their health information. See the [CMS Fact Sheet](#) CMS will accept comments on the major provisions in this proposed rule until early April (exact date will be updated upon posting at the Federal Register).

OF POSSIBLE INTEREST

[‘You Want A Cookie?’: As Families Arrive En Masse, Border Agents Offer Snacks and Medical Checks](#) (Washington Post, 2/19/19)

[Health Coverage of Immigrants](#) (Kaiser Family Foundation Fact Sheet, 2/15/19)

[Why the Battle to Bring Back School Nurses Is Such A Big Deal for Health and Academics](#) (USC Annenberg Center for Health Journalism, 2/15/19)

[Build Your Own ‘Medicare for All’ Plan. Beware: There Are Tough Choices](#) (NY Times, 2/21/19 – limited number of articles per month without subscription).

[A Parent-To-Parent Campaign To Get Vaccine Rates Up](#) (NPR, 2/20/19)

[Facing My Own Mortality Renewed My Faith In The Common Struggle For Universal Health Care](#) (The Boston Globe. 2/25/19, by Rob Restuccia, former executive director of Community Catalyst and founder of Health Care For All)

We at Family Voices 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! Comments and questions can be directed to jguerney@familyvoices.org.

Yours truly,
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Director of Public Policy
Family Voices

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.