



FAMILY VOICES[®]

Washington DC Update
October 31, 2018

HAPPY HALLOWEEN!



See these [safety tips](#) from the American Academy of Pediatrics.

GREETINGS FROM WASHINGTON!

DON'T FORGET TO VOTE on this coming TUESDAY, Nov. 6, and urge your family, friends and neighbors to vote too.

- All U.S. Representatives, [one-third of U.S. Senators](#), and many [governors](#), [mayors](#), and other state, territorial, and local officials will be up for election or re-election.
- Find out [where you vote](#) on Election Day.
- Many jurisdictions have [same-day registration](#), so you may still be able to vote even if you haven't registered yet.
- Many jurisdictions also allow [early voting](#), so if it's inconvenient to vote on Election Day, you can vote before then. See [where to vote early](#).
- [Accommodations](#) are required for people with disabilities or people who do not speak English.
- For more information about voting, see www.vote.org (where you can register to vote) or <https://www.usa.gov/voting>.
- You can get voting information via telephone from www.usa.gov at [1-844-USA-GOV1 \(1-844-872-4681\)](tel:1-844-USA-GOV1) between 8:00 AM and 8:00 PM ET, Monday through Friday, except federal holidays. (No TTY number is available, but there is a [chat function](#).)

Your elected officials make many decisions that affect the daily life and long-term health and well-being of you and your family. During the next two years, Congress will be setting funding levels for many programs affecting the health, education and welfare of children with special health care needs and their families, and *may* again take up legislation to alter the Medicaid program and Affordable Care Act. **One Senator or Representative can make a difference in the outcome of a vote on legislation**, so do what you can to make sure that your Members of Congress will represent your views on these important issues!

ALSO REMEMBER:

The 6th annual [open-enrollment period](#) for people to select insurance plans begins on **Thursday, November 1**, and ends on Saturday, December 15. **Please see the end of this Update for resources.** The [TRICARE open season](#) runs from November 12 through December 10. The [Medicare open season](#) runs from October 15 through December 7.

[A little kindness in the face of hate: 'I'm Dr. Cohen': The Powerful Humanity of the Jewish Hospital Staff that Treated Robert Bowers](#) (Washington Post, 10/30/18)

UPCOMING WEBINARS AND CALLS

NEW [Guardianship: Consider the Alternatives](#)

Wednesday, October 31, 12:00-1:00 pm ET

Vermont Family Network

NEW [The NIH All of Us Research Program and Precision Medicine: Reflections from a Rural State](#)

Wednesday, October 31, 2:00-3:30 pm ET

University of Montana Rural Institute for Inclusive Communities and the American Association on Health and Disability

Twitter chat: All of Us Includes Disability

Wednesday, October 31, 12:30 pm ET

American Association on Health and Disability (@AAHD1)

#AllofUsInclusion #JoinAllofUs

[State Strategies for Using Shared Plans of Care to Improve Care Coordination for Children and Youth with Special Health Care Needs](#)

Wednesday, October 31, 3:00-4:00 pm ET

National Academy for State Health Policy

Related article: [State Strategies for Shared Plans of Care to Improve Care Coordination for Children and Youth with Special Health Care Needs](#) (National Academy for State Health Policy, 10/29/18); related blog post [Why Shared Plans of Care Are Critical to Coordinated Care and How States Are Implementing Them](#) (NASHP, 10/29/18)

[Creating Change through Leadership: Two Extraordinary Leaders, a Mother and Daughter's Experiences Promoting Racial Equity](#)

Thursday, November 1, 1:30-3:00 pm ET

Trust for America's Health

SERIES [2019 Assister Readiness Webinars](#), from the Centers for Medicare and Medicaid Services (CMS). For more information about the series, see the "Resources for Open Enrollment" section at the end of this Update. Details are not yet available, but the next webinars should be:

- Nov. 2 - Helping Consumers Apply and Enroll in Coverage
- Nov. 9 - Making Coverage Accessible

To receive invitations to the live webinars and notifications when new material is posted, email ASSISTERLISTSERV@cms.hhs.gov with "Add to listserv" as the subject.

Community Care Coordination Systems: Leveraging Technology to Close the Loop

Tuesday, November 6, 2:00-3:30 pm ET

Nemours Children's Health System

NEW A Conversation on the Effect of Payment Models in Children's Health Care

Wednesday, Nov. 7, 1:00-2:00 pm ET

Lucile Packard Foundation for Children's Health

Electronic Visit Verification (EVV) Stakeholder Open Door Forum

Wednesday, November 7, 1:00-3:00 pm ET

Centers for Medicare and Medicaid Services (CMS)

Participant Dial-In Number: 1-(800)-837-1935; Conference ID: 33979177

[More CMS information about EVV](#)

NEW It Takes a Village (about addressing Utah's Native Hawaiians/Pacific Islanders' high rates of infant mortality)

Thursday, November 8, 11:00 am ET

Utah Office of Health Disparities

Maternal Opioid Misuse (MOM) Model - Overview

- **Thursday, [November 8](#), 12:00-1:00 pm ET**
- **Thursday, [December 6](#), 12:00-1:00 pm ET**

Centers for Medicare and Medicaid Services (CMS)

For more information, please visit the [Maternal Opioid Misuse \(MOM\) Model](#) webpage.

NEW SERIES Implementation of the Federal [Settings Criteria](#) for Home and Community-based Services (HCBS)

Administration on Community Living, Department of Health and Human Services (HHS)

- **Thursday, November 8, 2:00-3:30 ET**
[Innovative State Approaches to Promoting Compliance with the Federal HCBS Settings Criteria](#)
- **Thursday, November 29, 2:00-3:30 ET**
[Promising State Strategies for Working with Providers to Meet the HCBS Settings Criteria & Promote Optimal Community Integration](#)
- **Thursday, December 13, 2:00-3:30 ET**
[After Receiving Final Statewide Transition Plan Approval: Tackling the Ongoing Systems-Change Work that Remains](#)

SERIES Coordinating All Resources Effectively Award

Children's Hospital Association

- **[CARE Award: Transforming the Delivery System](#)**
November 14, 2:30-4:00 pm ET

- [CARE Award: Family Partners for Better Care](#)
December 18, 2:30-4:00 pm ET

Past webinar slides and recordings:

- [CARE Award: Stabilizing the Cost of Care](#)
- [CARE Award: Optimal Care Design](#)

[Creating a Vision for Adulthood](#)

Thursday, November 29, 12:00-1:00 pm ET

Vermont Family Network

THE ADMINISTRATION

New HRSA Data Website

The Health Resources and Services Administration (HRSA) has unveiled a new data and information website at <https://data.hrsa.gov/>. The website user can find health centers and health shortage areas, and can obtain [fact sheets](#) about HRSA activities at the national, state, county, or regional level, or by congressional district. Data are also available in interactive [maps](#) and through customizable data queries.

Updated: Proposed rule on immigrant “Public Charge” determinations

As first reported in the [September 26 Update](#) (p. 3), the Department of Homeland Security (DHS) is proposing to change the way in which determinations are made about the likelihood that an immigrant is or will become a “public charge,” and thus should *not* be admitted to the U.S. or granted a green card. Under the [proposed rule](#), receiving benefits such as non-emergency Medicaid services, food stamps (SNAP), and housing benefits for a certain period of time in the previous three years (counting only periods after the effective date of the *final* rule), or receiving a certain level of cash payments, would be viewed as evidence that someone may become a “public charge.” Other factors would also be considered, including age (being younger than 18 or elderly are negative factors), family income, English proficiency, and health status (having a serious health condition is a negative factor unless the person has private insurance or other means to cover the costs). Therefore, advocates fear that the rule would significantly deter people, including children, from accessing Medicaid and other important safety-net programs. *Note:* Receiving services under the Individuals with Disabilities Education Act (IDEA) or school-based Medicaid services would NOT be counted as a factor in public-charge determinations. Benefits received by an immigrant’s family members would NOT be considered in determining whether that person is or might become a public charge.

Public comments. Since this is such a far-reaching proposal, **it is important that as many individuals as possible submit comments for the record** about how it would impact them or the populations they work with. **Comments will be accepted on [this page of Regulations.gov](#) through **December 10 at 11:59 pm EST**.** Below are links to the rule and various (fairly short and simple) explanations and analyses:

- [Proposed rule](#) (in October 10 Federal Register). Please note that, on **page 51174** of the Federal Register, the **administration asks for comments about how to treat receipt of public benefits by**

children in general, and specifically **whether to add CHIP enrollment** as part of public-charge determinations.

- [Proposed Changes to Public Charge and FAQ](#) (*Center for Law and Social Policy/National Immigration Law Center, 10/10/18*)
- Explanation from the [September 26 Washington Update](#)
- [Changing Public Charge Immigration Rules: The Potential Impact on Children Who Need Care](#) (*California Health Care Foundation, 10/22/18*) [Researchers predict that the new rule would cause between 700,000 and 1.7 million children in need of medical attention to lose access to or experience delays in receiving Medicaid or CHIP benefits, including as many as 333,000 kids with at least one life threatening condition.]
- [The Health Impact of the Proposed Public Charge Rules](#) (*Health Affairs Blog, 9/27/18*)
- [Proposed Changes to “Public Charge” Policies for Immigrants: Implications for Health Coverage](#) (*Kaiser Family Foundation, 9/24/18*)

Updates Regarding the Detention of Immigrant Children:

[HHS Reviews Refugee Operations as Trump Calls for Border Crackdown](#) (Politico, 10/23/18)

[Hundreds of Migrant Children Held In U.S. Tent City for Months: Filings](#) (Reuters, 10/22/18)

WORTH REPEATING: Family Voices Immigration Toolkit

The Family Voices [Immigration Toolkit](#) includes everything families, physicians and other professionals need to know about providing medical information to immigration officials, which may be needed to argue for allowing a child with special health care needs or the child’s parent to stay in the U.S.

CONGRESS

Recess

Congress is in recess until November 13. This is a good time to visit your Senators and Representatives in their local offices, or attend public events, to educate them about children with special health care needs, the needs of their families, and your state’s programs to help CYSHCN and their families, including Family-to-Family Health Information Centers and the Title V block grant. You can find contact information for your Members of Congress at www.contactingcongress.org. You can find town halls and other public events at which your Members of Congress will appear at <https://townhallproject.com/>.

[Republicans Look to Safety-Net Programs as Deficit Balloons](#)

(New York Times, 10/26/18)

This article talks about possible congressional action after the election. As has been the case historically, many Members of Congress think that it important to trim the deficit by cutting “entitlement” spending. The most expensive entitlements are Social Security, Medicare and Medicaid. Given the popularity of Social Security and Medicare, Medicaid is a likely target for changes, as it was last year when Congress considered proposals to reduce federal Medicaid spending by funding for the program via a block grant or per capita cap.

MEDICAID AND CHIP NEWS, INFORMATION AND RESOURCES

As reported earlier, the president has signed into law the bipartisan “SUPPORT for Patients and Communities Act” ([H.R. 6](#)). This blog post explains how the Medicaid provisions in the new law will help children. [How Would Medicaid Provisions of New Law to Address Opioid Epidemic Impact Children?](#) (blog of the Georgetown Center on Children and Families, 10/24/18).

AFFORDABLE CARE ACT

Open Enrollment – See the end of this Update for resources to help assisters and consumers.

REMEMBER: 2019 Open Enrollment runs from Nov. 1 through Dec. 15, 2018.
{Please see the end of this Update for consumer and enrollment-assister resources.}

Important message from HHS regarding Find Local Help

Assisters are encouraged to ensure their listings on [Find Local Help](#) are accurate in preparation for Open Enrollment, which begins on November 1st. A Quick Reference Guide for Assisters on how to access and update listings on Find Local Help using the Upkeep Tool can be found [here](#).

Some Information for Consumers:

- [6 Common Open Enrollment Mistakes and How to Avoid Them](#) (TIME, 10/29/18)
- [What to Watch Out for During Open Enrollment](#) (CNBC, 10/27/18)
- [The Ins and Outs of High-Deductible Health Care Plans](#) (Minn. Public Radio, 49-minute audio story, 10/29/18)

Other News

Effect of Recently Announced Administrative Policies on the Sale of Health Insurance

As reported in [last week's Update](#), the administration issued a proposed rule that would allow small employers to offer reimbursement for employees to purchase individual insurance plans, which could boost the sale of individual policies in ACA marketplaces. Also last week, the administration established new guidance that will let states more easily get waivers to permit the sale of insurance policies that are less robust than those otherwise required under the Affordable Care Act. A recent article explains how new policies could have opposite effects on the health insurance marketplace: [With One Hand, Administration Boosts ACA Marketplaces, Weakens Them with Another](#) (Kaiser Health News, 10/30/18).

TRICARE

[TRICARE Open Season](#) runs from November 12 through December 10.

[ECHO Benefit Year Changes to Calendar Year](#) (10/17/18)

[Prepare for TRICARE Open Season: Compare TRICARE Plan Costs with Cost Comparison Tool](#)

(10/19/18)

[Compare 2019 FEDVIP Dental, Vision Plans Ahead of Open Season](#) (10/4/18)

OTHER NEWS, INFORMATION, AND RESOURCES

FDA Asks For Comments on Labeling Sesame Ingredients in Foods

The Food and Drug Administration (FDA) has issued a "[Request for Information](#)" requesting input from the public about whether it should require that sesame be listed as an ingredient on food labels to help protect those with sesame allergies. They are especially seeking input from about the prevalence and severity of sesame allergies and the prevalence of sesame-containing foods sold in this country. Comments are due no later than December 31, 2018. See [Statement from FDA Commissioner Scott Gottlieb, M.D., on the FDA's new consideration of labeling for sesame allergies](#) (FDA press release, 10/29/18).

[State Strategies for Shared Plans of Care to Improve Care Coordination for Children and Youth with Special Health Care Needs](#)

(National Academy for State Health Policy, 10/29/18) (See webinar on this topic in "Upcoming Webinars," above.)

[The MOM Model: New CMS Initiative Aims to Improve Systems of Care for Pregnant and Postpartum Women with Opioid Use Disorder](#)

(blog of the Georgetown Center on Children and Families, 10/25/18)

Medicare Drug Prices

On October 25, the president unveiled a [plan](#) ([explanation](#)) intended to reduce drug prices in the Medicare Part B program. Comments are due on December 29. See [Trump Administration Unveils Plan to Lower Medicare Part B Prices by Basing Costs on Other Countries' Pricing](#) (FierceHealthcare, 10/25/18).

OTHER RESOURCES FROM AROUND THE GOVERNMENT

[From the Substance Abuse and Mental Health Services Administration \(SAMHSA\)](#) [New Tool Offers Hope To People Experiencing Early Serious Mental Illness and Their Families](#)

[From the HHS Office of Civil Rights](#)

[OCR Launches Public Education Campaign About Civil Rights Protections in Response to the National Opioid Crisis](#)

[From the Centers for Disease Control and Prevention \(CDC\)](#)

[Duchenne Muscular Dystrophy: New Resource to Guide Care](#)

From the Department of Education Office of Civil Rights

WORTH REPEATING: Guidance on Bullying

On October 21, the Assistant Secretary for Civil Rights in the U.S. Department of Education issued a 13-page [letter](#) outlining the obligations of a school when a student with an IEP or 504 Plan is bullied.

YOUR INPUT SOUGHT

Nominations Sought for Federal Family Caregiving Advisory Council – due Dec. 3

The Secretary of Health & Human Services (HHS) has posted a [Notice](#) requesting nominations for individuals to serve on the Family Caregiving Advisory Council, which was created by the [RAISE Family Caregivers Act](#). Pursuant to the law, the Council's 15 members will include at least one person from each of the following categories: family caregivers; older adults who need long-term services and supports; individuals with disabilities; health care and social service providers; providers of long-term services and supports; employers; paraprofessional workers; state and local officials; accreditation bodies; veterans; and as appropriate, other experts and advocacy organizations engaged in family caregiving. Nominations must be submitted by **Monday, December 3, 2018**. A description of the Council, member responsibilities, and procedures for submitting comments can be found in the [10/12/18 Federal Register](#).

Comments on the “Public Charge” Rule – due Dec. 10

[Please see article above under “Administration.”]

Since this is such a far-reaching proposal, **it is important that as many individuals as possible submit comments for the record** about how it would impact them or the populations they work with.

Comments will be accepted on [this page of Regulations.gov](#) through **December 10 at 11:59 pm EST.**

Comments on New Standards for ACA Innovation Waivers (§1332 waivers)

– due Dec. 24

On October 22, the Centers for Medicare & Medicaid Services (CMS) and the U.S. Department of the Treasury (collectively, the Departments) released new [guidance](#) ([press release](#); [fact sheet](#)) on waivers authorized by section 1332 of the Affordable Care Act (ACA), which was intended to let states design innovative ways to insure their residents. The newly termed “State Relief and Empowerment Waivers” will let states allow the sale of insurance policies that do not meet all of the ACA's standards, using criteria that are more flexible than those established by the Obama administration. These alternative plans may provide less robust coverage than would be allowed under the previous guidance, and would not necessarily have to cover pre-existing conditions. The new standards became effective on October 22, but the **administration is [accepting comments](#) on them through December 24**. For background information, see [Why the New ACA Waivers Matter](#) (*Axios*, 10/23/18); [CMS Expands Flexibility for State ACA Innovation Waivers](#) (*FierceHealthcare*, 10/22/18); [Trump Officials Make It Easier for States to Skirt Health Law's Protections](#) (*New York Times*, 10/22/18). For a very thorough explanation of the new guidance, see [Administration Proposes Significant Policy Changes for State Insurance Markets through New 1332 Waiver Regulations](#) (*National Academy for State Health Policy blog*, 10/23/18).

Comments to FDA about Sesame Allergies – Due Dec. 31

(See more in “Other News,” above.)

The Food and Drug Administration (FDA) has issued a “[Request for Information](#)” requesting input from the public about whether it should require that sesame be listed as an ingredient on food labels to help protect those with sesame allergies. Comments can be submitted [here](#).

ANNOUNCEMENTS

MCHB Grand Challenges – deadline extended to Nov. 9 for CYSHCN Challenge

As reported earlier, the Maternal and Child Health Bureau will award four prizes in a [Grand Challenges](#) competition to develop innovative, low-cost, and scalable solutions to improve the health of mothers and children across the U.S. **The [Care Coordination for CSHCN Challenge](#) deadline has been extended until Nov. 9 at 8:00 pm ET (5:00 pm PT)**. This challenge supports the creation of technology innovations to meet the needs of children with special health care needs and their families. You only need a 5-page description that meets the [Submission Requirements](#) and [Review Criteria](#) for the CSHCN challenge. Submissions for the challenge relating to [Remote Pregnancy Monitoring](#) are due on **Nov. 27** (5:00 pm ET) [*sic*] and submissions for the challenge relating to [Opioid Use Disorder in Pregnant Women and New Moms](#) are due **Nov. 19** (5:00 pm ET) [*sic*]. The Childhood Obesity Challenge is no longer accepting applications.

American Academy of Pediatrics Reaffirms Care Coordination Policy Statement and Offers Implementation Resource for Pediatric Clinicians

The American Academy of Pediatrics (AAP) recently reaffirmed its policy statement on care coordination. For pediatric clinicians, care coordination is an important component of the medical home model and has been shown to improve family and provider satisfaction, facilitate a child’s access to services, and improve health care outcomes. The [Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems](#) (AAP Policy Statement) has laid the foundation for various care coordination tools and resources developed collaboratively by the National Center for Care Coordination Technical Assistance (NCCCTA) and the National Center for Medical Home Implementation. These free resources include:

- [Pediatric Care Coordination Curriculum](#) which demonstrates [the principles, key concepts and activities that are necessary to successfully provide care coordination to patients and families](#)
- Care coordination [Webinar Series](#) that showcase real-world experiences from diverse health care providers with the common goal of capturing the value of care coordination using the [Care Coordination Measurement Tool \(CCMT\)](#) and [Adaptation and Implementation Guide](#)
- [Promising Practices](#) that demonstrate the practical application of care coordination to enhance the care provided to patients/families.

These tools and resources are available in the public domain to assist clinicians and other practice staff with care coordination activities. Additional care coordination tools and resources can be found on the [NCCCTA Web site](#). For technical assistance and support, contact medical_home@aap.org.

OF POSSIBLE INTEREST

[For the Disabled, A Doctor’s Visit Can Be Literally an Obstacle Course — And the Laws Can’t Help](#)

(Washington Post, 10/28/18)

[Ninth Child Dies in New Jersey Facility Suffering Adenovirus Outbreak](#) (ABC News, 10/28/18)

[Guns Send Over 8,000 US Kids To ER Each Year, Analysis Says](#) (Associated Press, 10/29/18)

RESOURCES FOR OPEN ENROLLMENT

2019 Open Enrollment Runs from November 1 through December 15, 2018

Plans sold during Open Enrollment start January 1, 2019. After December 15, consumers can enroll in 2019 health insurance only if they qualify for a [Special Enrollment Period](#).

[Federal Health Insurance Exchange 2019 Open Enrollment](#) (CMS press release with information and resources)

Some Resources for Consumers:

- [6 Common Open Enrollment Mistakes and How to Avoid Them](#) (TIME, 10/29/18)
- [What to Watch Out for During Open Enrollment](#) (CNBC, 10/27/18)
- [The Ins and Outs of High-Deductible Health Care Plans](#) (Minn. Public Radio, 49-minute audio story, 10/29/18)
- [Short-Term Plans Resource](#): A palm card designed by the Colorado Consumer Health Initiative to inform consumers about the pitfalls of short-term limited duration health plans.
- [Health Plan Comparison Worksheet](#): A worksheet created by Cover Missouri to adequately compare health plans available on and off of the ACA marketplace.

Resources for Assisters:

The [2019 Assister Readiness Webinar Series](#) is a supplement to the 2019 web-based Assister Certification Training, and is intended for assisters operating in the Federally-facilitated Marketplace (FFM), but assisters operating in State-Based Marketplaces that use the Federal Platform (SBM-FPs) may also find the Week 2, Week 3, and Week 4 modules helpful. The series will be delivered in weekly installments, each of which will include several on-demand educational modules, and a corresponding LIVE Friday webinar that will recap the week's topics and give participants a chance to ask questions.

To receive invitations to the live webinars and notifications when new material is posted, email ASSISTERLISTSERV@cms.hhs.gov with "Add to listserv" as the subject. Module/Webinar topics by week:

- [Week 1- Assister Roles and Responsibilities](#)
- [Week 2- 2019 Individual Marketplace Overview](#) – **Register**. (See details in "Upcoming Webinars" section above.)
- Week 3- Helping Consumers Apply and Enroll in Coverage
- Week 4- Making Coverage Accessible

Other Resources for Assisters:

- Marketplace Assister Training [Resources](#)
- [Technical Assistance Resources](#)
- CMS Marketplace [Applications & Forms](#)
- CMS [Outreach and Education](#) Resources
- [Marketplace.CMS.gov Page](#)

- [CMSzONE Community Online Resource Library Pilot for Marketplace Assisters](#)
- [Find Local Help](#)

Health Insurance Marketplace Call Center: 1-800-318-2596 (TTY: 1-855-889-4325). For customer service support, to start or finish an application, compare plans, enroll or ask a question. Available 24 hours a day, 7 days a week. Closed Memorial Day, July 4th, and Labor Day.

CACs and Navigators should call their dedicated phone lines so the Call Center can better track the needs of assisters. The Assister Line can also help with password resets and can help with access to non-application SEPs. Contact your Navigator Project Officer (for Navigators) or your designated organization leadership (for CACs) for more information on the Assister Line.

- Navigator Marketplace Call Center line: 1-855-868-4678
- CAC Marketplace Call Center line: 1-855-879-2683

SHOP Call Center: For customer service support, including assisting employers and employees apply for and enroll in SHOP. 1-800-706-7893 (TTY: 711). Available M-F 9:00 am-5:00 pm EST. Closed New Year’s Day, Martin Luther King Day, Memorial Day, July 4th, Labor Day, Veterans Day, Thanksgiving and the day after, and Christmas.

[More outreach and enrollment resources from Enroll America.](#)

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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,
 Janis Guerney
 Director of Public Policy
 Family Voices

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