



FAMILY VOICES[®]

Washington DC Update
September 25, 2019

Greetings from Washington!

The big news from last week: Congress has passed the Autism CARES Act, and it is expected to be signed by the president. More good news: the US Customs and Immigration Services has decided to continue processing medical “deferred action” requests, which will make it easier for immigrants to stay in this country for their own or family members’ medical treatment. Congress continues to work on addressing the problems of high prescription drug prices and surprise medical bills. Read about these topics and more in this week’s Update.

Special Enrollment Period Available for Victims of 2019 Hurricane Dorian

Consumers who qualified for an another enrollment period, such as a special enrollment period (SEP) or Open Enrollment Period (OEP), but were unable to complete a Marketplace application, plan selection, or enrollment process due to Hurricane Dorian, may have access to an Exceptional Circumstances Special Enrollment Period (SEP). These individuals have 60 days from the end of the FEMA-designated incident period to complete their 2019 enrollment and request a retroactive start date based on when he or she would have picked a plan if not for Hurricane Dorian. Consumers will be considered “impacted” and eligible for this SEP if they reside, or resided at the time of the hurricane, in any of the [counties declared](#) as meeting the level of “individual assistance” or “public assistance” by the Federal Emergency Management Agency (FEMA). See [2018 guidance](#) on Special Enrollment Period (SEP) policy for consumers impacted by an emergency or major disaster. **Assisters, agents, and brokers can help affected consumers by contacting the Marketplace Call Center at 1-800-318-2596 or TTY at 1-855-889-4325 to request enrollment using this SEP.**

It’s a busy month -- SEPTEMBER IS:

- [Sickle Cell Awareness Month](#) (HHS Office of Minority Health)
- [National Childhood Obesity Month](#) (CDC)
- [Food Safety Education Month](#) (CDC)
- Hispanic Heritage Month (September 15-October 15) ([HHS Office of Minority Health](#); [CMS](#))
- [National Preparedness Month](#) (Administration for Community Living; [FEMA](#))
- [National Recovery Month \(Recovery Month\)](#) (SAMHSA)

NOTE:

- **The 2020 Open Enrollment Period is November 1, 2019 to December 15, 2019.** See the [list of 2019 CMS Navigator grantees](#).
- [Get Ready: TRICARE Open Season, Federal Benefits Open Season Begins Nov. 11](#)

UPCOMING WEBINARS AND CALLS

[Business Acumen Webinar: Use Measurement to Demonstrate Performance](#)

Wednesday, September 25, 12:30-1:30 pm ET

[HCBS Business Acumen Center](#)

[NEW 2019 National Preparedness Month](#)

Wednesday, September 25, 1:00 pm ET

Centers for Disease Control and Prevention (CDC)

[NEW Putting it Together: Healthcare and the Path to Employment](#)

Wednesday, September 25, 3:00-4:30 pm ET

Social Security Administration, Ticket to Work program

[NEW Ask TRICARE](#)

Thursday, September 26, 1:00-2:00 pm ET

TRICARE; Military OneSource

[NEW Disaster Preparedness: Resilience, Readiness, and Resources for Patients and Caregivers](#)

Thursday, September 26, 2:00-3:00 pm ET

California Partnership for Access to Treatment

[NEW Violence and Mental Illness: The Real Story](#)

Thursday, September 26, 2:00-3:00 pm ET

Association of University Centers on Disabilities

[NEW Measuring What Matters with Patients and Families](#)

Friday, September 27, 3:00-4:00 pm ET

Patient and Family-Centered Care Partners (PFCCPartners)

[NEW Medicaid Retroactive Coverage: What's at Stake for Older Adults When States Eliminate this Protection?](#) *[Should be applicable to other populations also.]*

Tuesday, October 1, 2:00-3:00 pm ET

Justice in Aging and AARP Public Policy Institute

See also [Justice in Aging Brief: Medicaid Retroactive Coverage: What's At Stake When States Eliminate It.](#)

[SERIES: Health Reform: Beyond the Basics](#)

- **[Part I: Determining Households & Income for PTC & Medicaid](#)**

Tuesday, October 1, 2019 | 2:00 pm ET

- **[Part II: Premium Tax Credits](#)**

Thursday, October 3, 2019 | 2:00 pm ET

- [Part III: Auto-Renewal Process for 2020 on Healthcare.gov](#)
Tuesday, October 8, 2019 | 2:00 pm ET
- [Part IV: Preventing & Resolving Data Matching Issues](#)
Thursday, October 10, 2019 | 2:00 pm ET
- [Part V: Plan Design](#)
Tuesday, October 15, 2019 | 2:00 pm ET
- [Part VI: Plan Selection Strategies](#)
Thursday, October 17, 2019 | 2:00 pm ET

For more resources, please visit the Health Reform: Beyond the Basics website at www.healthreformbeyondthebasics.org. Contact at beyondthebasics@cbpp.org.

NEW [Keeping Medicaid's Promise for Children with Special Health Care Needs](#)

Wednesday, October 2, 3:00-4:30 pm ET

Manatt Health, Robert Wood Johnson Foundation, Lucile Packard Foundation for Children's Health

NEW [Medicare for People Living with Paralysis](#)

Wednesday, October 2, 3:00-4:30 pm ET

The Center for Medicare Advocacy and the Christopher & Dana Reeve Foundation

SERIES [Person-Centered Planning and Practice](#)

National Quality Forum/Administration for Community Living; Centers for Medicare and Medicaid Services

Friday, December 13, 2019, 1:00-3:30 pm ET

Monday, January 6, 2020, 1:00-3:30 pm ET

Monday, February 3, 2020, 12:30-3:00 pm ET

Monday, June 1, 2020, 1:00-3:30 pm ET

[past] Friday, September 6, 2019

THE ADMINISTRATION – IMMIGRATION

Medical Deferred Action – Administration Reverts to Previous Policy

As explained in the [September 18 Update](#), the U.S. Customs and Immigration Services (USCIS) agency, part of the Department of Homeland Security (DHS), sent [letters](#) to individuals in August to tell them that the agency would stop processing “deferred action” requests for those seeking to stay in the U.S. for a special reason, such medical treatment for themselves or family members. On September 11, the Civil Rights and Civil Liberties Subcommittee of the House Committee on Oversight and Reform held a [hearing](#) on this issue, and later announced that it would hold a second hearing. Shortly thereafter, USCIS officials notified the committee that it would reverse its new policy, and continue to process deferred action requests. See [Administration Appears to Reverse Decision to Deport Critically Ill Children After Pressure from Oversight Committee](#) (Press release from the House Oversight and Government Reform Committee, 9/19/19); [DHS Walks Back Decision to Halt Medical Deportation Relief](#) (Politico, 9/19/19).

Public Charge

More details about the final rule and resources to educate families are at the end of this Update.

As explained in the [September 18 Update](#), the Department of Homeland Security (DHS) issued a [final rule \(PDF version\)](#) on August 14 that will broaden the scope of the so-called “public charge” test for certain types of immigrants seeking visas or green cards. The result will be that more people will be denied entry to or permanent residency in the U.S. because they will be deemed a potential “public charge.” Some of the factors that will count against immigrants in this assessment are health status (e.g., disabilities); age (under 18 or over 65); and the use of certain government benefits, including SNAP (food stamps), housing assistance, and Medicaid (with certain exceptions and exemptions for children and pregnant women). The final rule goes into effect at 12:00 a.m. ET on October 15, 2019.

Bills have been introduced in both the House and Senate to block implementation of the rule, but it seems unlikely that such legislation will be approved in the Senate. The rule is also being challenged in court by a number of states. On September 10, [18 disability and civil rights organizations](#) filed an [amicus \(friend of the court\) brief](#) in the support of the legal challenges to the rule.

HHS Inspector General Reports on Detained Children

On September 4, the Office of the Inspector General (OIG) of the Department of Health and Human Services (HHS) released two reports - [Unaccompanied Alien Children Care Provider Facilities Generally Conducted Required Background Checks but Faced Challenges in Hiring, Screening, and Retaining Employees \(summary\)](#), and [Care Provider Facilities Described Challenges Addressing Mental Health Needs of Children in HHS Custody \(summary\)](#). See the [OIG press release](#) for more information.

CONGRESS

The big news this week is the passage of the Autism CARES Act. Congress is still working to develop legislation prescription drug prices and on surprise medical bills, both of which are contentious. Meanwhile, Congress and the White House have agreed to a temporary spending bill through November 21. That “continuing resolution” (with current funding levels) is expected to be enacted by the end of the fiscal year on September 30 in order to avoid a government-shut down.

Autism CARES Act Passes Congress

On September 19, by unanimous consent, the Senate passed the House version of the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019 ([H.R.1058](#)), which reauthorizes the law for five more years. As summarized in the [press release from Senators Robert Menendez \(D-NJ\) and Mike Enzi \(R-WY\)](#) (quoting Diana Autin of the NJ F2F/Family Voices), the bill:

- Authorizes research under the National Institutes of Health (NIH) to address the entire scope of autism spectrum disorder;
- Designates regional centers of excellence for ASD research and epidemiology;
- Directs activities to increase public awareness of autism, improve the ability of health providers to use evidence-based interventions, and increase early screening and detection;
- Authorizes \$23.1 million to the CDC for developmental disability surveillance and research;
- Authorizes \$50.6 million to the Health Resources and Services Administration (HRSA) for education, early detection, and intervention, and allows HRSA to prioritize new grant applicants in rural or underserved areas;

- Authorizes \$296 million for the National Institutes of Health (NIH) for research;
- Requires the Department of Health and Human Services (HHS) to provide a report to Congress on the health and well-being of individuals of all ages with ASD and other developmental disabilities.

The legislation also extends the [Leadership Education in Neurodevelopmental and Related Disabilities \(LEND\) programs](#), Developmental Behavioral Pediatrics (DBP) Training Programs, the “Learn the Signs. Act Early” campaign, and the Autism and Developmental Disabilities Monitoring (ADDM) Network. In addition, the bill increases the minimum number of self-advocates to serve on the Interagency Autism Coordinating Committee (IACC). The president is expected to sign the bill.

Appropriations

As reported in the [September 18 Update](#), Congress has not yet passed its spending (appropriations) bills for FY 2020, which begins on October 1, 2019. To avoid another government shut-down, a short-term spending bill (“continuing resolution”) was approved by the House on September 19. It will fund the government through November 21. The Senate is expected to approve the bill this week and the president is expected to sign it. See [House Passes Short-Term Spending Bill, Punting Shutdown Fight to November](#) (Washington Post, 9/19/19).

The bills to fund the Departments of Labor, Health and Human Services (HHS), and Education have been developed in both the House and Senate. If each chamber passes its bill, a conference committee will have to resolve the differences, and the White House will have to agree to the final bill as well. (Administration officials are usually involved in the conference negotiations too.)

Prescription Drug Prices

As explained in the [September 18 Update](#), both Congress and the administration seem serious about addressing high prescription drug prices, but there are significant differences of opinion within Congress on how to do so. Last week, House Speaker Nancy Pelosi (D-CA) unveiled [the House Democrats' version of drug-price legislation](#), the “Lower Drug Costs Now Act of 2019” ([H.R. 3](#) text; [summary](#)). See [Understanding The House Democrats’ Drug Pricing Package](#) (Health Affairs Blog, 9/19/19). Under that bill, Medicare would annually negotiate prices for at least 25 brand-name drugs, tying the rates to costs in other developed countries. This is an approach that the president had suggested earlier. Nevertheless, Senate Majority Leader Mitch McConnell (R-KY) has said that the plan is “dead on arrival” in the Senate. See [McConnell Warns Pelosi's Drug-Pricing Plan Is DOA](#) (Politico, 9/19/19). Pharmaceutical companies are heavily lobbying and publicly advertising against this approach.

Several House committees have jurisdiction over drug-pricing legislation. On September 25, there is a [hearing before the House Energy & Commerce Committee](#) on several of the bills. On September 26, there is a [hearing before the Committee on Education & Labor](#).

In July, the Senate Finance Committee approved a [bill](#) that would require drug makers that raise prices faster than inflation to pay the difference back to Medicare. See [Understanding The Senate Finance Committee’s Drug Pricing Package](#) (Health Affairs Blog, 7/26/19).

Surprise Medical Bills

As reported in the [September 18 Update](#), lawmakers seem serious about protecting consumers from surprise medical bills, but there are very different approaches on how to do so. In both the House and Senate, there are multiple bills on this issue. See [Comparing Federal Legislation on Surprise Billing](#) (To the Point, Commonwealth Fund blog, 9/19/19). As explained in a [blog post from the Bipartisan Policy Center](#), the Senate bill – which was reported out of the Committee on Health, Education, Labor & Pensions (HELP) in July -- would essentially tie out-of-network charges to a federal benchmark of median in-network rates for a geographic area. The House Energy & Commerce Committee bill, reported out of the Health Subcommittee -- would use that method with back-up arbitration between insurers and providers. In general, hospitals and doctors prefer an arbitration-only approach, while insurers prefer a benchmark approach. A good explanation of the issue can be found in [The Health 202: Doctors Are Gaining the Edge in Fight over Surprise Medical Billing](#) (Washington Post, 9/23/19).

ACA NEWS, INFORMATION, AND RESOURCES

NOTE: The 2020 Open Enrollment Period is November 1, 2019 to December 15, 2019.
[View a list of 2019 CMS Navigator grantees.](#)

Worth Repeating: [Health Insurance That Doesn't Cover the Bills Has Flooded the Market Under Trump](#) (Bloomberg Business Week, 9/17/19).

MEDICAID NEWS, INFORMATION, AND RESOURCES

The Children's Hospital Association has developed a 10-minute online "learning module" to explain the basics of the Medicaid program - [Medicaid 101](#). It is available for anyone to use, and sharing is encouraged.

MEDICAID WAIVERS – TENNESSEE “BLOCK-GRANT” PROPOSAL

Worth Repeating: As reported in the [September 18 Update](#), Tennessee has developed a waiver [proposal \(explanation, text, instructions for submitting comments\)](#) to change its method of federal Medicaid funding to a modified block grant. See [Tennessee Becomes First State with a Plan to Turn Medicaid into a Block Grant](#) (Washington Post, 9/17/19). **The state public-comment period is open through October 18.** After the proposal is submitted to the Centers for Medicare and Medicaid Services (CMS), there will be another public comment period.

Under block grants or per capita caps, there is a danger that a state will not have sufficient funds to cover all beneficiaries and/or services, particularly if a state suffers an economic downturn making more people eligible for Medicaid. The Centers for Medicare and Medicaid Services (CMS) has been developing guidance for states that would like to apply for waivers to receive their federal Medicaid payments as "block grants" or "per capita caps." See [With Trump's Blessing, Some States Aim to Cap Medicaid Rolls](#) (Pew Stateline, 7/24/19).

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](#).

TRICARE

From TRICARE Benefits Updates:

- [Get Ready: TRICARE Open Season, Federal Benefits Open Season Begins Nov. 11](#) Sept. 18, 2019
- [Bring Your TRICARE Benefit Questions to September 26 Webinar](#) Sept. 18, 2019
- [TRICARE Dental and Medical: Separate Programs, Separate Enrollments](#) Sept. 23, 2019

[Sign up for TRICARE email updates.](#)

Connect with TRICARE on [Facebook](#) and [Twitter](#).

OTHER NEWS AND INFORMATION & RESOURCES

- [First Drug for Peanut Allergy Nears FDA Approval](#) (Healthline, 9/16/19)
- [The Future of Coverage for American Indian and Alaska Native Children](#) (Georgetown Center for Children and Families blog post, 9/17/19)
Report: [Promoting Health Coverage of American Indian and Alaska Native Children](#) (Georgetown University Center for Children and Families, 9/17/19)
- [Assistance for Indian Children with Severe Disabilities](#)
[Benefits.gov](#) has announced a recent update to the information on this webpage.
- [Helping Emergency Rooms Prepare for Kids in Crisis](#) (new HRSA toolkit)
- [CYSHCNet Develops Standards of Compensation for Family Partners in Research From Lucile Packard Foundation](#). The knowledge and experience of families and youth is invaluable to research about children with special health care needs (CSHCN), but family contributions have not been consistently recognized or compensated. CYSHCNet, a national research network founded in 2017, has developed [a standard of compensation for youth and family partners](#) (PDF) who participate on a research team, noting possible roles and responsibilities, as well as the type of support and compensation family members might expect. CYSHCNet also has created a companion piece, [a standard of compensation for research teams](#) (PDF) on how researchers can identify, orient, support, and compensate family and youth partners.
- **Worth Repeating: Family and Medical Leave for IEP Meetings**
In an August 8 [opinion letter](#), the Department of Labor concluded that the Family Medical Leave Act (FMLA) covers an employee's attendance at a school meeting where their child's individualized education program (IEP) will be discussed.

YOUR INPUT SOUGHT

NEW Due October 2. Department of Education: [Technical Assistance to Improve Postsecondary Transition Services](#) The Department of Education's Office of Special Education and Rehabilitative

Services (OSERS) is seeking public input on the way it provides technical assistance (TA) to State Education Agencies (SEAs), Local Educational Agencies (LEAs), State Vocational Rehabilitation Agencies (SVRAs), and Career and Technical Education (CTE) on improving postsecondary transition services to all students and youth with disabilities. Additionally, OSERS seeks input on how best to strengthen and expand coordination and collaboration with OSERS Parent Training and Information Centers and other relevant TA centers.

NEW Due October 31. HHS/NIH, *All of Us* Research Program: [Request for Information \(RFI\) to Inform Tribal Collaborations](#). The *All of Us* research program seeks input on Tribal Nation issues and concerns, including the importance of proper handling of AI/AN biospecimens in accordance with Tribal beliefs and traditions, challenges with handling data from self-identified AI/AN individuals, and educating the research community on avoidance of stigmatizing research.

FDA Patient Representatives

Are you a patient or caregiver who wants to get involved at FDA? Contact [the Patient Affairs Staff \(PAS\)](#) or follow us on Twitter [@FDAPatientInfo](#).

SPECIAL ANNOUNCEMENT

StoryBooth: Opportunity to Share YOUR Health Care Story!

Do you have a story about your health care experiences you'd like to share? Family Voices is working with the University of Pittsburgh to help promote their StoryBooth project. This is a research project designed to collect stories from patients and families about their experiences with health care. The hope is that by listening to the stories of people they can improve health care for others. In addition to stories from adults (patients and caregivers), they would like to include some stories from youth directly (must be at least 18 years old to participate). Stories are collected through phone interviews and then will be added to their [website](#). You can listen to some of the stories they've collected there. People who share their stories will be asked where they heard about the project, and then ask for permission to share the story with the source. Family Voices would love to be able to share your stories as well. Click on the links for two posters for general information and contact information:

- [General audience](#)
- [Youth audience](#)

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## **SOME RESOURCES AND DETAILS ABOUT THE FINAL "PUBLIC CHARGE" RULE**

### **ADDED SINCE THE LAST UPDATE:**

- [Specialized Resources for Advocates and Service Providers](#)
- [Who Does "the Public Charge Test" Apply To? \(sample cases\)](#)
- [Estimated Impacts of Final Public Charge Inadmissibility Rule on Immigrants and Medicaid Coverage](#) (Kaiser Family Foundation, 9/18/19)
- [Final "Public Charge" Rule: Implications for Medicaid](#) (National Association of Medicaid Directors webinar materials).



The following resources are among the many that [can be found on the website of the coalition Protecting Immigrant Families](#) (The National Immigration Law Center and the Center for Law and Social Policy).

**This information is NOT legal advice.** For information about a specific case, please contact an immigration expert. [Find help in your area.](#)

- [Let's Talk About Public Charge](#) (Learn more about what “public charge” is and how to talk about these changes with immigrants) - [Spanish](#), [Arabic](#), [Hindi](#), [Chinese](#)
- [Getting the Help You Need](#) (See how “public charge” will impact an immigrant based on immigration status, and what they should do) - [Spanish](#), [Arabic](#), [Hindi](#), [Chinese](#), [French](#)
- [You Have Rights: Protect Your Health](#) (An overview for mixed-status families when it comes to going to the doctor or enrolling in health insurance) - [Spanish](#), [Arabic](#), [Chinese](#), [French](#), [Hindi](#), [Korean](#), [Vietnamese](#) (PIF)

#### DETAILS ABOUT THE FINAL RULE:

- [Changes to Public Charge: Analysis And Frequently Asked Questions](#) (Updated September 2019)
- Excerpts from [Let's Talk About Public Charge](#):

**This public charge inadmissibility test does not apply to every immigrant.** Exempt immigrants include: refugees; asylees; survivors of trafficking, domestic violence, or other serious crimes (T or U visa applicants/holders); VAWA self-petitioners; special immigrant juveniles; and certain people paroled into the U.S. Benefits received when people are in one of these statuses will not be counted against them. **And lawful permanent residents (green card holders) are not subject to a public charge test when they apply for U.S. citizenship.**

**Use of public benefits will not automatically make you a public charge.** Immigration officials must look at all your circumstances in determining whether you are likely to become a public charge in the future. This includes your age, health, income, assets, resources, education/skills, family you must support, and family who will support you.

**Positive factors, like having a job or health insurance, can be weighed against negative factors, like having used certain benefits or having a health condition.** Either way, you will have a chance to show why you are not likely to rely on certain benefits in the future.

**This public charge test does not consider benefits used by family members.** Most immigrants who are applying for a green card are not eligible for the benefits listed in the rule. And benefits used by eligible family members are not counted unless the family members are also applying for a green card. Health care, nutrition, and housing programs can help you and your children remain strong, productive, and stable.

**The rule does not consider any newly listed benefits that are used before October 15, 2019.** Benefits that were previously excluded from the public charge test (such as Medicaid and SNAP) will only be considered if they are received after October 15, 2019. The new rule applies only to people whose green card application was filed (postmarked or submitted electronically) on or after October 15, 2019. Using benefits now can help you or your family members become healthier, stronger, and more employable in the future.

**Your personal information is protected.** Federal and state laws protect the privacy of people who apply for or receive health care coverage, nutrition, economic support, or other public benefits. Applications for public programs should not ask for information about the immigration status of people applying to get benefits for another person in their family or the household. Benefit agencies may share information with other government agencies only for purposes of administering their programs, with limited exceptions. You can provide only the information necessary and should never misrepresent anything when completing public benefit applications or dealing with any government agency.

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](mailto:jguerney@familyvoices.org).

Yours truly,  
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Family Voices

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