Greetings from Washington!
Congress came back from its August recess last week and is working to develop legislation on surprise medical bills and prescription drug prices, among other things. While the Washington Update was on recess, the administration issued its final rule on the “public charge” (immigration) issue,* and announced a significant change in the way it will handle the immigration status of people coming from other countries to seek health care in the US. In other news: the Department of Labor has determined that the Family Medical Leave Act covers an employee's attendance at IEP meetings, and the Department of Transportation issued a final statement on service animals aboard aircraft. Read about these topics and more in this week’s Update.

* Resources and details about “public charge” are at the end of this Update.

Reminder: September 23 is the deadline to submit comments on proposed changes to food stamp eligibility rules.

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)
- 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. Visit here for a list of 2019 CMS Navigator grantees.

- Get Ready: TRICARE Open Season, Federal Benefits Open Season Begins Nov. 11

UPCOMING WEBINARS AND CALLS

NEW 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 [no link]
Wednesday, September 25, 1:00-2:00 ET
Centers for Disease Control and Prevention (CDC)

NEW 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
  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 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

Public Charge
For many years, people who want to immigrate to the U.S. or obtain permanent residency (a “green card”) have been assessed to determine whether they are likely to become a “public charge” (dependent on government assistance). As explained in earlier Updates, the administration proposed last fall to broaden the factors that go into “public charge” assessments. The Department of Homeland Security (DHS) issued the final rule (PDF version) on August 14; it goes into effect at 12:00 a.m. Eastern Time on October 15, 2019.

Under rules in effect since 1999, someone is deemed a public charge only if they are “primarily dependent on the Government for subsistence, as demonstrated by either the receipt of public cash assistance for income maintenance or institutionalization for long-term care at Government expense.” Under the new rule, the public charge determination will also take into account certain characteristics
of the immigrant (e.g. health, age, income, and skills, including English language skills), and receipt of specified non-cash benefits for non-exempt individuals. (Some immigrants are exempt.) These programs include:

- Supplemental Nutrition Assistance Program (SNAP, “EBT” or “Food Stamps”)
- Federal Public Housing and Section 8 assistance
- Medicaid (except for emergency services, children under 21 years, pregnant women, and new mothers)
- Cash assistance programs (like SSI, TANF, General Assistance)

Services that are not specifically listed will not be counted in the new public charge test. These include WIC, CHIP, school lunches, food banks, shelters, and many others.

The use of benefits by family members of an immigrant will NOT be considered in the public charge assessment of that immigrant. Nevertheless, child health advocates are concerned that many immigrants will be deterred from enrolling their children in Medicaid, WIC, and other important programs. See 23 Children's Health, Advocacy Organizations Join Together to Oppose Public Charge Final Rule; Final Public Charge Rule: Analysis and Potential Implications (archived webinar, State Health and Value Strategies, 9/3/19); Changes to “Public Charge” Inadmissibility Rule: Implications for Health and Health Coverage (Kaiser Family Foundation, 8/12/19).

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.

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

Medical Deferred Action

For many years, the U.S. Customs and Immigration Services (USCIS) agency, part of the Department of Homeland Security (DHS), has been responsible for considering “deferred action” requests from individuals who have a special reason to stay in the US, such as sick children undergoing medical treatment and their families. Deferred action allows someone to stay in the country even if they would otherwise be subject to deportation, before any deportation proceedings are instituted.

In August, USCIS field offices began to send letters to people who were applying or re-applying for deferred action to tell them that the agency would no longer be processing these requests, and that they would be subject to deportation proceedings if they did not leave the country within 33 days. It is still possible for someone to be granted a stay (waiver) from deportation during the deportation process, which is conducted by the Immigration and Customs Enforcement (ICE) agency of DHS. The letters did not mention this, however, and ICE said it had not been aware of the USCIS policy change and would not be changing its own policies so that people could get deferments prior to the commencement of deportation proceedings. See Feds Can't Agree On Which Agency — If Any — Handles Medical Deportation Deferrals (WBUR, 8/28/19). After negative publicity - see, e.g., Immigrant Children with Life-Threatening Illnesses Facing Possible Deportation (CBS News, 8/28/2019) - USCIS announced on September 2 that it would continue to process deferred action requests that were pending as of August 7, but would not do so for other requests. On September 11, the Civil Rights and
Civil Liberties Subcommittee of the House Committee on Oversight and Reform held a hearing on this issue. The administration has not made any further announcements about the matter.

CONGRESS

In the health world, there are several big issues pending in Congress: appropriations for the Department of Health and Human Services; reauthorization of certain Medicaid and Medicare provisions and the Autism CARES Act; and new legislation to address prescription drug prices and surprise medical bills.

Appropriations and “Health Extenders”

Back to Basics: Congress Tries to Keep Government Lights On (Associated Press, 9/17/19)

Although an agreement to set federal spending levels was reached earlier this year, Congress has not yet passed its spending (appropriations) bills. To avoid another government shut-down, it is likely that a short-term spending bill will be enacted to keep programs running until late November. That legislation may also extend other programs, such as certain expiring Medicaid and Medicare provisions (“health extenders”), respite programs, and the Autism CARES Act (see below).

Autism CARES Act

The Autism CARES Act authorizes autism research, coordination, public awareness, surveillance, interdisciplinary health professional training, and the Interagency Autism Coordinating Committee. It also reauthorizes the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, which provide graduate level interdisciplinary training and services to children with disabilities. The Autism CARES Act will expire on September 30, 2019, unless it is reauthorized. A bill (H.R. 1058), which would reauthorize CARES for five years, passed the House on July 24, 2019, but the Senate bill (S. 427) has not been taken up in the Senate. At this point, it is expected that either a short- or long-term reauthorization of CARES will be included in a short-term bill that extends a number of programs until late November.

Lifespan Respite Care

Legislation to reauthorize the Lifespan Respite Care program (H.R. 2035) was passed by the House in July, but the Senate bill (S. 995) has not yet been taken up in the Senate.

Prescription Drug Prices

Both Congress and the administration seem serious about addressing high prescription drug prices, but there are significant differences on how to do so. Senate Finance Committee Chairman Chuck Grassley (R-IA), and the Ranking Democratic committee member, Ron Wyden (D-OR) proposed one solution, which was approved by the committee (with a number of Republicans opposed). Under that bill, drug makers that raise prices faster than inflation would have to pay the difference back to Medicare. House Speaker Nancy Pelosi (D-CA) is expected to unveil a bill with a different approach (according to a leaked draft) – to allow Medicare annually to negotiate prices on 250 brand-name drugs that lack at least two generic or biosimilar competitors, tying the rates to costs in other developed countries. See Insurers, Hospitals Could Reap Benefits from Leaked Drug Price Bill From Pelosi (FierceHealthcare, 9/10/19); Pelosi Tries to Split Trump, Republicans Over Drug Pricing (Politico, 9/10/19). Drug makers are pushing hard against any type of price controls.
**Surprise Medical Bills**

As with prescription drug prices, lawmakers seem serious about protecting consumers from surprise medical bills, but there are different approaches to doing so. In both the House and Senate, bipartisan bills have been reported out of relevant committees. In the Senate, the *Lower Health Care Costs Act* (S. 1895) was sponsored by Senate HELP Committee Chairman Lamar Alexander (R-TN) and Ranking Member Patty Murray (D-WA). In the House, the *No Surprises Act* (H.R. 3630) was sponsored by House Energy & Commerce (E&C) Committee Chairman Frank Pallone (D-NJ) and Ranking Member Greg Walden (R-OR). See Pallone-Walden press release. As explained in a blog post from the Bipartisan Policy Center, the Senate bill would essentially tie out-of-network charges to a federal benchmark of median in-network rates for a geographic area. The House bill would use that method with back-up arbitration between insurers and providers. But hospitals and doctors prefer an arbitration-only approach. (It has been discovered that unidentified television ads have been funded by private equity firms that own physician groups that contract with hospitals for ER and other services.) Two other committees also have jurisdiction in the House – the Ways & Means Committee and the Education & Labor Committee. The latter has postponed a tentative meeting due to divisions among its members about which approach to take. See House Panel Delays Vote on Surprise Medical Bills Legislation (The Hill, 9/17/19).

**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.

**Sales of Short-term, Substandard Insurance Plans**

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**

**Decline in Children’s Public Insurance Coverage**

On September 10, the Census Bureau released a report showing that the number of people with insurance in the U.S. has declined for the first time in a decade. The percentage of people with health insurance coverage for all or part of 2018 was 91.5 percent, lower than the rate in 2017 (92.1 percent). Children are among the populations that saw a decrease in insurance coverage. The percentage of uninsured children under the age of 19 increased by 0.6 percentage points between 2017 and 2018, to 5.5 percent. Most of this decrease was because children’s Medicaid and CHIP coverage rates declined. In 2018, 35.3% of children had Medicaid or CHIP, compared with 36.5% in 2017. See Children’s Public Health Insurance Coverage Lower Than in 2017 (United States Census, 9/10/19). See Multiple Factors Appear to Be Contributing to Children’s Rising Uninsured Rates (National Academy for State Health Policy, 9/1/19).

**MEDICAID WAIVERS**

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). Although the guidance has not yet been released, Tennessee has already developed a waiver...
proposal to implement a modified block grant. See Tennessee Becomes First State with a Plan to Turn Medicaid into a Block Grant (Washington Post, 9/17/19). 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 downtown making more people eligible for Medicaid.

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
FYI: US Military Families Face Challenges Getting Healthcare for Kids (Reuters, 8/5/19)

From TRICARE Benefits Updates:
• 9/12/2019 Get to Know Your TRICARE Young Adult Plan
• 9/9/2019 Get Ready: TRICARE Open Season, Federal Benefits Open Season Begins Nov. 11
• 9/4/2019 Traveling or Moving? TRICARE Dental Program Goes With You
• 8/29/2019 Get to Know Your US Family Health Plan Coverage
• 8/27/2019 Keep DEERS Up to Date to Use TRICARE
• 8/21/2019 Be Disaster Prepared With TRICARE
• 8/19/2019 Deactivating? Learn About Your TRICARE Coverage Options as a National Guard or Reserve Member
• 8/15/2019 TRICARE Coverage After Gaining or Losing Other Health Insurance
• 8/12/2019 TRICARE Covers You, Even When You’re Separating from the Service
• 8/8/2019 Start the School Year Right With Healthy Teeth
• 8/6/2019 Get Kids Ready for Back-to-School With Preventive Health Care

Sign up for TRICARE email updates.
Connect with TRICARE on Facebook and Twitter.

OTHER NEWS AND INFORMATION
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.

U.S. Department of Transportation Issues Final Statement of Enforcement Priorities Regarding Service Animals on Flights
(Dept. of Transportation press release, 8/8/19; scroll down the webpage to see a summary of the Final Statement.)
The U.S. Department of Transportation (DOT) has issued a Final Statement of Enforcement Priorities Regarding Service Animals, which states that the Department’s Enforcement Office does not intend to take action against an airline for asking users of service animals to provide documentation related to...
vaccination, training, or behavior, so long as it is reasonable to believe that the documentation would assist the airline in making a determination as to whether an animal poses a direct threat to the health or safety of others. The Enforcement Office will monitor airlines’ animal documentation requirements to ensure that they are reasonable. The Final Statement also addresses other issues, such as species limitations, containment, advance notice, and check-in requirements for Emotional Support and Psychiatric Service Animals.

**U.S. Department of Transportation Announces Formation and Membership of the Air Ambulance and Patient Billing Advisory Committee**

(Dept. of Transportation press release, 9/13/19)
The U.S. Department of Transportation (DOT) has announced the formation of the Air Ambulance and Patient Billing Advisory Committee (AAPB Advisory Committee) to advise the Secretary about issues relating to air ambulance services and patient billing. The 13-member committee includes a representative of patient advocacy groups from the American Heart Association. Updates on the AAPB Advisory Committee can be found [here](#).

**YOUR INPUT SOUGHT**

**Due September 23: Food Stamp Eligibility**
The administration has issued a [proposed rule](#) that would restrict state flexibility to expand eligibility for food stamps. The Department of Agriculture estimates that the proposal would make 3.1 million people ineligible for the program. Comments may be submitted through September 23 via [this page on Regulations.gov](https://www.regulations.gov). See also [Trump Proposal Would Push 3 Million Americans Off Food Stamps](https://www.washingtonpost.com); [Trump Administration Moves to End Food Stamps for 3 Million People](https://www.bloomberg.com).(Washington Post, 7/23/19); [Trump Administration Moves to End Food Stamps for 3 Million People](https://www.bloomberg.com).(Bloomberg, 7/23/19).

**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](https://twitter.com).

**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](https://www.storybooth.org). 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](#)
OF POSSIBLE INTEREST

Air Ambulances Woo Rural Consumers with Memberships That May Leave Them Hanging (Kaiser Health News, 9/16/19)

Racial Disparity in Care Starts With Youngest, Frailest Patients (US News, 7/29/29)

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SOME RESOURCES AND DETAILS ABOUT THE FINAL “PUBLIC CHARGE” RULE

RESOURCES:

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.

Yours truly,
Janis Guerney
Director of Public Policy
Family Voices

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